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Life story work - a new approach to the person centred supporting of older adults with an intellectual disability in Norway.

A qualitative study of the impact of life story work on storytellers and their interlocutors

Britt-Evy Westergård

Thesis submitted for the degree of Doctor of Philosophy

The University of Edinburgh

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PART II

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Abstract

Older Norwegian adults with an intellectual disability are today more integrated into society than earlier generations. Some represent the last of the generation that experienced and can talk about childhoods in central institutions and about living under the World War II Nazi regime. The closure of Norwegian institutions, which took place in the1990s, was based on social valuation theories. The post-closure situation for people with intellectual disabilities, their staff and local authorities was very different form what they had experienced previously, local authorities being responsible for providing person-centred services. This thesis examines whether life story work represents an effective approach to the person-centred support of older adults with an intellectual disability, through examining the impact of this work on services users ('storytellers') and their life story work supporters ('interlocutors'). 'The life story model of identity' developed primarily by the American psychologist and professor Dan P. McAdams, is a major contribution to the thinking of this study. The model emphasises the importance of service providers' understanding and knowledge of their service users' life stories. A combination of critical realism and interpretative phenomenology analysis is advanced as a suitable joint philosophical framework for investigating the impact life story work has on both storytellers with intellectual disabilities (aged 45+) and on the interlocutors they personally chose from their staff group. The Delphi technique was used in a preparatory phase of interviews of six experienced life story workers from three different countries. A Participatory Action Research (PAR) approach was used to prepare the intervention, to develop the LSW programme and for pre- and post-interviews. 38 participants from day centres and residential settings in Norway took part in the study. The results indicate that even staff who had known storytellers for a long time learned new and valuable information. They came into possession of a better understanding of the service users' behaviour and the interlocutors' attitudes to service users were changed by the experience of carry out life story work with them. The interlocutors stated that they considered life story work to be 'important' in today's services. The storytellers experienced increased feelings of safety and greater awareness of their abilities, life span (roots) and of themselves as a person (identity and personal development). They expressed pride in their life story work and appreciated the time they had spent talking and working alone with their interlocutors. Storytellers and interlocutors both said that life story work had brought them closer together and the love and appreciation they had for each other was a clear result of the time they had spent together. The eight week programme was, however, also challenging for the interlocutors who had problems finding the opportunity to conduct two hours work a week without interruption from other contextual influences.

Declaration

This is to certify that the work contained within has been composed by Britt-Evy Westergård and is entirely her own work. No part of this thesis has been submitted for any other degree or professional qualification.

Britt-Evy Westergård

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Knowing others is intelligence;

knowing yourself is true wisdom.

mastering others is strength;

mastering yourself is true power

(Lao Tzu & Mitchell, 2006: 33)

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1 Introduction and objectives

> *"There are 650 million people with disabilities in the world who all have their unique story to share." (Smith 2009: 1793).*

In Norway, there are an unknown number of persons with intellectual disabilities (ID) who have unique stories to tell about their lives. Those who are aged 40 years and over are the last generation who can speak about life in Norwegian central institutions, which were all closed down from 1991 to 1996. This generation has longer life expectancy than previous generations and the municipalities that took over the services in 1991 now have more elderly adults with ID to take care of today than in the past (Westergård and Larsen 2004).

In old age, people continue to refashion themselves and *"re-narrate their lives in the wake of predictable and unpredictable life changes"* (McAdams 2001:117). In her study of adult development and ageing, Bernice Levin Neugarten found that there was no one 'right' way for people to grow old. McAdams claims that older people create the clearest palette for understanding personality over long periods of time. They become increasingly different from one another when they age and they become more and more like 'themselves'. (Hooker and McAdams 2003; Neugarten 1964). These facts make it interesting to ***study the impact of LSW and the identity of older adults with ID***.

As a researcher with 36 years of experience in this field as a social educator, behaviour therapist, special pedagogue, leader and teacher, the most important knowledge I have about disabilities today is derived from persons with disabilities themselves. I have had the pleasure of having people with disability as my colleagues and friends.

In my work at a Norwegian national program for ageing and intellectual disability (2004- 2014), a leader for the Brobygger Ligaen user-organisation (bridge-building- league) told me that people with ID should be provided with courses in personal development. Since then I have wondered how this can be achieved, because it would be a new idea in those services which have mainly focused on care and training. There is also a recognised lack of programmes, strategies, evidence-based methods and service models that cover the broad field of ageing and ID (EASPD 2006; Janicki et al. 1999; Janicki, McCallion and Dalton 2000; Watchman 2003; Wilkinson et al. 2004).

Much of what we know about optimal ageing focuses on the life-long importance of health-related behaviour. Surprisingly little is focussed on personality, which arguably is *"…the driving force behind all antecedents of successful aging…"* (Hooker and McAdams 2003: 296). In the past, a more comprehensive view on the relationship of personality to ageing has been advanced. Researchers have therefore been encouraged to consider not only traits but also life stories, goals and developmental aspects of personality in adulthood (ibid).

Local services take care of a number of older adults with ID whose personal history can reveal challenging experiences involving asymmetrical power relationships but few lasting ties or relationships. In the literature, there are testimonies of oppression, discrimination and injustice and a number lack family and friends living nearby that might have helped them to locate themselves within their own trajectory/history (Atkinson, Jackson and Walmsley 1997; Bentley et al. 2011; Fjermeros 2009; Ingham 2006).

Public services that only focus on a person's disability emphasise factors that make people segregated.

The individuality of people with a disability is sometimes ignored; they are named or 'labelled' by their diagnosis or as a group. The relevance of this study is related to the important task of providing an individual perspective and individuality that stimulates our understanding of personal identity. One unique factor in a person's life is therefore the individual's life story (Hooker and McAdams 2003; McAdams 2001). This means that knowledge of the life stories of service users is an important start point for building a person centred approach. These facts provide a basic argument for the relevance of this study, which is also supported by the current Norwegian and international requirement on adopting a person centred approach within local health and social services (Helse- og omsorgsdepartementet 1999; UN 2006).

The next section says more about the central terms, concepts and definitions this study is based on.

1.1 Population and ageing in people with intellectual disabilities

Despite a variation, the most common estimate of the proportion of the population with ID is between 1.5 - 3 percent (Walsh 2008). This means between 75,000 and 150,000 people in Norway are estimated to have ID. International and demographic projections suggest that the numbers will rise by 14 percent between 2001 and 2021 and that numbers will rise at both ends of the age spectrum (APS Group Scotland 2012).

The Norwegian Ministry of Health and Social Affairs suggests that almost 40 percent (30-60,000) of people with ID aged 40 years and

over receive public services (Sosial- og helsedepartementet 2000; 2004). The only study in Norway directly covering people with ID aged 40 and over claims there are 7,312 that receive housing services from Norwegian municipalities (Westerberg 2013). The gap between these figures for the number of people with ID aged 40 and over means that Norway lacks knowledge on the size of this age group. This makes it difficult to make good plans for the future for the ageing population with ID in Norway.

People with ID, without major additional disabilities, have the same life expectancy as the general population (Haveman and Stöppler 2004; Jahnsen et al. 2004; Margallo-Lana et al. 2007; van Schrojenstein Lantman-De Valk et al. 2000). But it is a fact that persons with ID are more exposed to health problems and are often more vulnerable to developing psychosocial difficulties (Bittles et al. 2002; Haveman et al. 2009; IASSIDD 2002; Janicki and Dalton 1998; Prasher and Janicki 2002).

1.1.1 Ageing in people with intellectual disabilities

Visual and hearing diseases and impairments, heart disease, diabetes and dementia are frequent among people with Down syndrome.

Studies suggest that changes in personality and behaviour in mid-life, with no other explanation, could be very early clinical markers of dementia that becomes apparent some years later (Ball et al. 2006; Haveman 2004; Margallo-Lana et al. 2007; Nilsson 2002; Nilsson 2006; Patja et al. 2000; Prasher 2005; Prasher and Janicki 2002; Solberg et al. 2006).

46 percent of persons with Down syndrome aged 50 or older have epilepsy and late detection is often related to early signs of *Alzheimer disease* (Prasher 2005) which occurs to a greater extent and at an earlier age in this group (Haveman et al. 2009; Strydom et al. 2009). Age of onset is in the mid-50s and the prevalence increases until the age of 60, after which it appears to drop. This may possibly be due to the increased mortality associated with dementia (Strydom et al. 2009).

Pain occurs frequently in the elderly. But there is less knowledge about how elderly people with disabilities express their pain. For example, cerebral palsy has a clear physical influence on premature ageing - from as early as 25-30 years of age. It often causes problems with pain, concentration and immobility (Jahnsen et al. 2004; Prasher and Janicki 2002). Studies show that pain is not often on the checklist of health personnel and not something the closest providers consider when health status and behaviour change (Haveman et al. 2009; Kerr, Cunningham and Wilkinson 2006; Mencap 2007). Experience also shows that ordinary health service staff lack practice and knowledge in how to communicate with and understand persons with ID. This can result in the mainstream health system providing poor services and the continuing inability of health services to properly detect pain or diseases in those with ID (Ellingsen and Neset 2007; Mencap 2007).

In an EU based health study called the POMONA II[1] project, 65 percent of the participants with ID used one or more forms of medication (Walsh 2008). Polypharmacy is frequent and there is a lack of knowledge about the medical effects of polypharmacy on persons aged 67 and over and also on people with brain damage. Medication may have other effects on brain injuries and studies show that mental disorders increase with psychotropic medication (Haveman et al. 2009; Hviding and Mørland 2003; Patrick and Kwok 2007). The impact of wrong medication frequently includes a restricted desire or ability to communicate and reduction in general motivation and attention span (Lyng 2006; Solberg et al. 2006).

Health problems which may have been present since childhood, are likely to remain undetected thereby increasing the chances of impaired learning, communication and personal development (Haveman 2004). These health problems may be detected when people tell their stories to service providers who have the insight and competence to understand what it means.

A perception of good physical health is associated with good mental health. Subjective well-being and personality influences the person's perception of mental and physical health (Friedman, Kern and Reynolds 2010). It is thought that persons with a mild degree of ID have one to two times' higher probability of experiencing mental problems than people with a moderate degree of ID.

[1] An EU study about Health Indicators for People with Intellectual Disabilities: Using an Indicator Set

There is, however, a divergence between studies of mental health. People with a severe degree of ID have a three to four times' higher probability than the normal population (Eknes 2000; Patrick and Kwok 2007; Solberg et al. 2006).

Other studies have also show that changes in older adult (ID) behaviour have been understood to be 'personality', 'mental deficiency' or 'ageing' and are not further examined (Strydom et al. 2009). This also applies to health problems related to loss and grief (Brilman and Ormel 2001), which often are misunderstood as an early sign of dementia (Nilsson 2002; Nilsson 2006; Patti and Tsiouris 2003; Patti, Amble and Flory 2005)

Connections between life events and mental problems are well-documented (Hastings et al. 2004; Hulbert-Williams and Hastings 2008; Monaghan and Soni 1992; Owen et al. 2004). So is the correlation between depression and unpropitious life conditions (Brilman and Ormel 2001; Kraaij, Arensman and Spinhoven 2002; Orell and Bebbington 1995; Sable, Dunn and Zisook 2002). For example, growing up in an institution involves a high risk of stress, which may lead to psychological difficulties (Eknes 2000, see 1.2).

Norwegian governmental papers confirm the challenges a number of older adults with ID have faced during their lives associated with often unforeseen interactions from their integrated social life and personal networks (Arbeidsdepartementet 2002: 2.7.1). For example, a statutory reform (The Responsibility Reform) in 1991 passed the responsibility for services to people with ID from the county to municipalities. A number experienced a considerable loss of adequate leisure activities and socialisation/inclusion services (Tøssebro 2011).

Another issue is the hard life some of the residents had to endure when they moved out of institutions that they had lived in for most of their lives. Studies tell how adults with essential qualities for being integrated, were stressed and unhappy with their 'new life'. They felt they had to work hard to hide their disability and their past, and a number were ashamed of growing up in an institution (Tronvoll 2000).

Surveys show that older people with ID now typically have a poor social network beyond the immediate family and paid caregivers (Brevik and Høyland 2007; Jacobsen 2007; Tøssebro 2010). They have fewer social networks than younger people with an ID and older adults with ID lack a system of support when they grieve for friends and family who die. They tell about a longing for a network they can trust (Brandt 2006; Due 2006-2007; Thorsen 2005; UAU 2007). There are reasons to believe that older adults with ID are more exposed to loneliness than other older adults without disability. There is a lack of data on this and of studies of persons' feelings/experiences of loneliness (Bugge and Thorsen 2004; Sjørengen et al. 2005; Tøssebro and Lundeby 2002; Westerberg 2013).

1.2 Historical context

Humans are always influenced by their environment and experiences. When people talk about their lives, such influences are often revealed through the stories they tell. This section presents some of the influences which today's older adults with ID are and have been subjected to.

The history gives us an impression of how services for people with ID have developed. It may also help us to understand the challenges today's services are facing and the influences these challenges have on people's lives. History tells us much about the present and helps us decide our future.

Telling stories from the past may help people remember events and give life to multifaceted feelings that influence their present lives. A number of today's older adults with ID have strong memories from World War II and the time immediately after that. They also have recollections from the institutions they lived for a number of years. Staff knowledge of their service user's historical context is beneficial. It provides them with an understanding of the events the storyteller may have grown up with. This knowledge allows them to better understand and have valuable conversations about the stories that they tell. Staff can better help people to tell their stories by asking relevant questions and be more understanding of those who refuse to tell their stories.

When the oldest of today's population with ID were children, the attitude of society was that they were a threat to society; never capable of self-support or managing their own affairs. Until the 1940s, most people with ID who could not be taken care of by their family were placed in psychiatric hospitals or private care (Culling 2008; Ericsson 1982; Tøssebro 1992).

The building of institutions at the end of 18th century laid the foundations for the childhood memories of some of today's older adults with ID. Norway's institutions were not as large and as extensive as in other countries in Europe and USA. The first institution for those with the most severe disabilities started in 1898.

Emma Hjort's Home is today a museum and still bears the name of the woman who started the institution. The Norwegian Red Cross was the first to start a day centre - in 1938 (Fjermeros 2009; Romøren and Sandvin 2001; Thingsrud 2002).

The relative paucity of institutional care turned out to be a benefit for adults with ID about 40 years later, when the war came to Norway. World War II came to Norway in 1940 and ended in 1945. Because of the lack of institutional care in Norway, the 'euthanasia programs' (T4) did not have as serious consequences as in many other countries. The Germans registered 70,273 people with a physical or 'mental' disability who they had murdered in 1940 and 1941. For example, in Austria almost everyone in institutions was murdered (BBC 2011; Bell 2011; Sørlie 2011). The living conditions in Norwegian institutions before, during, and immediately after the war were, however, very difficult and the mortality rate was high (Fjermeros 2009).

In Norway, the Germans were encouraged through the 'Lebens-bornprogramme' to have sexual relationships with Norwegian women (Regulation of 26 October 1942: About caring for children that were born, in Kristiansen 1999). As a result of rapes, prostitution and random acquaintances, 8,020 children were registered in this program when the war ended. Some lived with their families or were sent to Germany. Many lived in Lebensborn orphanages such as Godthåb, Stalheim, Moldegård and Hurdals Verk. After the war, the priesthood in Norway regarded the children as a huge threat to society and wanted to send them out of the country. It is not known where most of these children were sent after the war. However, in 1946 twenty-three children arrived at Emma Hjort from various orphanages and foster homes.

The children were at their most sensitive age: two, three and four years old and only spoke German as they had spent their first years in strict orphanages with German staff (Borgersrud 2005; Fjermeros 2009; Kristiansen 1999; Olsen 1998; Olsen 1999; Tutvedt 2009).

Children who grew up in institutions during or right after the war, were influenced by the environment they lived in. Some were physically injured by other residents or by the staff and underdeveloped because of the lack of social and relational stimuli. The units were overcrowded, there was a lack of human resources, and very few staff had relevant education (Befring et al. 2004; Ericsson and Simonsen 2005; Tutvedt 2009).

PIC 1 & 2: Rooms in Emma Hjort's Home. Photo: Norway's Resistance Museum

1.2.1 Normalisation, deinstitutionalisation and integration

After World War II, institutionalisation in Norway began to increase before a change took place in society's view on the living conditions of people with ID. In the 1960's, institutions were increasingly seen as places that promoted passivity and isolation more than development. At this time, the idea that people with disabilities should be integrated

into ‘normal society’ became professionally accepted and politically supported (Helsedepartementet 1966-67). After this time, the institutions became smaller and were allocated more resources and more staff. Despite this criticism, institutions continued and were intensified during the 1970’s and 1980’s (Fjermeros 2009).

Normalisation, deinstitutionalisation and integration have been important concepts in Norwegian policy and in the development of today’s services for older adults with ID.

Most of today’s older adults with ID have experienced the impact of the paradigm shift that occurred in most countries of widespread deinstitutionalisation and the provision of more personal and individualised services. Some central contributors at this time were Erik Bank-Mikkelsen (Danish), Bengt Nirje (Swedish) and Wolf Wolfensberger (American), who introduced the concept of ‘normalisation’. They had a huge influence on the way the Norwegian service system developed. Through the work of Nirje and Bank-Mikkelsen, Scandinavia was the crucible for much subsequent work on normalisation. So too was the English speaking world.

Already in 1969, when the idea of ‘normalisation’ was known in Norway, Nirje claimed that older adults with ID should live close to where they had spent most of their life, the place they knew and where their networks and families were (Nirje 1969). Bank-Mikkelsen claimed that normalisation was ‘to live as normally as possible’. Nirje thought normalisation was to have a normal life-rhythm and cycle and Wolfensberger claimed normalisation was to have a valued social role (VSR). Wolfensberger deliberately used the term SRV instead of ‘normalisation’ to overcome historical problems that had always plagued this term (see 2.2). He claimed that SRV is more relevant to

the essence of its meaning (Thomas and Wolfensberger 1999; Wolfensberger 1983; Wolfensberger 1999b).

Norway was the last Nordic country to build institutions and was at the forefront of closing them (Mansell 2006; Romøren and Sandvin 2001; Tøssebro 1996). In 1985, a government evaluation committee (Sosialdepartementet 1985: Lossius II) concluded that institutions had to close and that the responsibility for services should be handed over to the municipalities. Normalisation led to the idea that services must be provided at the most local level possible and organised by the same agencies that provided services to the general population (Askheim 2008; Helsedepartementet 1989-1990; Romøren and Sandvin 2001; Tøssebro 2010).

It was hard for Norway to meet the ideologically oriented objectives of normalisation. Evaluations during and after the reform concluded that the explicit goals of normalisation and social integration were seldom reached (Tøssebro 1996; Tøssebro and Lundeby 2002). Surveys after the Responsibility Reform show that service users in the municipalities were seldom present when ideas and decisions about treatment and services were developed. Their knowledge was not valued and staff practised self-determination in an unstructured and random way (St.meld. nr. 21 1998-99). There is no public answer why this happened. One explanation may be that local politicians, who had the responsibility for organising services within their community after the institutions were closed, did not have the professional expertise because the expertise had previously been held by the institutions. There was little or no knowledge transfer to the new style of services.

Some people were never part of the Responsibility Reform. They had always lived with their families and received services' from local authorities. Others were hidden from society and did not show up before the 1980s or when their parents needed help because of their own issues of ageing (Fjermeros 2009). In Norway, this situation is called double ageing; when parents and children get ageing problems at same time (Thorsen and Hegna Myrvang 2008).

Contemporary services in the municipalities seem to have moved back to more centralised services provided by larger units. The requirement set by Parliament is, however, that these units must be smaller and not return to the practices of the past (Selvsagt 2010). Current criticism of the postmodern welfare state blurs the fact that market liberalism leads to greater inequality and marginalization of the weakest groups (Askheim 2008) – a criticism that might be even more relevant now after the financial crisis.

1.3 The context of where this study took place

Professional actors in most Norwegian health and social services are employed at national, regional and local levels. The most relevant level for this study is, however, the level of municipality responsibility, the service users and the central principles that guide their practice.

A municipality has, according to Norwegian legislation, a responsibility to provide support to people with ID from the cradle to the grave.

The municipalities are independent and are free to unrestrictedly decide the organisation of services and their priority, as long as they follow and meet the minimum requirement stipulated in Norwegian law.

Municipalities are obliged to organise day activities to prevent isolation, to activate and rehabilitate the users and as respite care for the family. Senior-centres for people with ID are a growing activity, but the municipality is not *obliged* to provide these special centres (Helsedirektoratet 2009). It is not known where and how many senior-centres there are in Norway today. Senior centres are especially important to adults who live at home with their parents, as a way to meet other people with ID and be a part of society (Thorsen and Hegna Myrvang 2008; Tøssebro and Lundeby 2002).

Municipalities are also obliged to organise accommodation with services for those who need extensive health and social services, which includes most older adults with ID (Helsedirektoratet 2009). In 2011, the vast majority (94.5 per cent) aged 40 and over lived in shared flats with their own apartment and some common rooms. Among these, less than 6 percent were living in flats especially designed for older adults with ID (Westerberg 2013).

There were 373 persons with ID in nursing/retirement homes. 11 of these nursing homes/units were designed especially for older adults with ID. Only 8.3 percent of the municipalities had adopted a specific political plan that covers care of the older population with ID. Around 90 percent of the municipalities reported they met this situation without any specific local policy/politically confirmed plan (Westerberg 2013). This is also recognised in Europe for older adults

with ID who are identified with a special need for attention and policy planning, systems of supports and rights (EASPD 2006: 3.3.b).

In the 1980s, most Norwegian municipalities introduced a service model with a *key worker* (in Norwegian: primær-kontakt) for each service users. This model is still used. A key worker often has the best knowledge about the service user, as well as their family and social network. The researcher's impression is that the key worker, in most cases, is the most important person for the service user; especially for those without family. It has not been possible in Norwegian literature reviews to find out how important the key worker and the functions they carry out are to service users. There is little research and few studies that cover the (Norwegian) person centred approach (PCA) in this field.

1.4 Terms and definitions used in this study

Terms and concepts that are briefly reviewed in this section are discussed more fully in sections two and three.

The definition of *disability* has changed over time and emphasises various aspects of the impairment. Today the most up to date definition is in *The Convention on the Rights of Persons with Disabilities* (UNCPRD):

> *"…disability is an evolving concept, and that disability results from the interaction between persons with impairments and attitudinal or environmental barriers that hinders their full and effective participation in society on an equal basis with others."* (United Nations 2006: 5, paragraph e).

The definition from WHO emphasises that intellectual disability is:

> *"…a significantly reduced ability to understand new or complex information and to learn and apply new skills (impaired intelligence). This results in a reduced ability to cope independently (impaired social functioning), and begins before adulthood, with a lasting effect on development."* (WHO 2010).

The Scottish Government definition is the one most appreciated in this study:

> *"People with learning disabilities have a significant, lifelong, condition that started before adulthood (before the age of 18), which affected their development and which means they need help to: understand information; learn skills; and cope independently."* (APS Group Scotland 2013: 21).

Additionally they say that people with ID can be so much more e.g. *"… a friend, a family member, a community activist, a student, a parent, an employee or employer to name just a few roles."* (ibid: 21).

Intellectual disabilities, is a subset of the term disability and is commonly used terminology in international research reports and in international associations (Walsh 2008). Intellectual disabilities with the abbreviation ID therefore is the preferred terminology used in this thesis.

According to the WHO, people are old when they are aged 60 and over (WHO 2004), while studies show that people with specific syndromes and neurological disorders e.g. Down Syndrome and cerebral palsy, have signs of ageing about 20-30 years earlier than others (Haveman and Stöppler 2004; Jahnsen et al. 2004; Patja et al. 2000; Prasher and Janicki 2002). Younger age groups e.g. 40, 45 or 50 years old, are therefore often included in studies about ageing in this field (IASSIDD 2005).

The lower age limit in this study is set to 45 years for the term *older adult*. Using biological age alone is difficult and there is no concise/agreed use of this term because people with ID are not *"…a homogeneous group with similar characteristics and similar needs."* (Haveman et al. 2009; WHO 2008: 11). The term older adults is also a preferred term in the International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD) reports (Haveman et al. 2009; Strydom et al. 2009).

A *person-centred approach*, hereafter abbreviated PCA, is a central concept in this thesis. The definition of PCA pays attention to the person's identity and life stories that are crucial to practising PCA. This is described in more detail in chapter 2.3.

Identity is in this thesis defined as (see also 2.4-6):

> *"Identity is a particular flavouring of peoples' self-understanding, a way in which the self can be arranged or configured…that a person's self-understanding is integrated synchronically and diachronically…into a meaningful psychosocial niche and provides his or her life with some degree of unity and purpose." (McAdams 2001b:102).*

The definition of life story work, hereafter abbreviated LSW and which this study is based on, is:

> *"In essence life story work involves gathering a variety of information on all aspects of the person's life, from personal experiences, feelings and thoughts on life changes, families, relationships, to more factual information on birthdays, schools, homes lived in , etc. … the intention is not to present a complete life-story of the client, but to highlight certain aspects of their lives, thus improving our understanding of the way in which they perceive everyday events/interactions."* (Hussain and Raczka 1997: 73).

Related terms about identity and life story work are clarified in section 2.4-8 and 3.2.3. The LSW programme developed in this study included one *storyteller* and one *interlocutor*. The storyteller is the person with ID, while the interlocutor a staff member in the storyteller's home place or day centre.

The interlocutor was chosen by the storyteller. Their task was to listen and motivate more than to decide, manage and make plans for the LSW they conducted together (see 3.7.1).

Impact is another central concept that is used in this thesis. From an individual perspective, an impact may be defined as being self-reported alterations in a participant's knowledge, behaviour, thoughts and feelings after LSW. An impact may be defined as: *"Positive and negative, primary and secondary long-term effects produced by a development intervention, directly or indirectly, intended or unintended"* (Garbarino and Holland 2009: vi).

1.5 Aims and objectives

The principal aim of this research is to *develop and applicate a model to promote LSW as a service in Norway*. To enable this, two secondary aims led the research process:

1) To evidence the impact of life story work on participants
2) To explore the contribution of life story work in the delivering of a person centred approach for older adults with intellectual disabilities in Norway

The aims set out above are achieved by providing evidence on the following objectives:

a. To explore LSW among experienced professionals in LSW in Norway and two other countries where LSW is frequently used, to create a basis for participatory action research of the LSW-programme, developed in this research
b. To engage the participants in developing and evaluating a LSW programme that seems suitable for Norwegian services

- Researching and analysing relevant literature on international LSW-models in relation to their usefulness in Norwegian services

c. To evidence the benefits/impact of LSW in older adults with ID and their interlocutors by
    - Analysing the process and outcomes of LSW on storytellers' identity, their personal development and their interlocutors' professionalism
    - Analysing the participants' experiences with LSW in this study and their perception of the importance of LSW in the services

The study was organised in two phases. The purpose of the first stage was to provide information by studying practice and theory on LSW to build up to the second stage. Based on the knowledge revealed in phase one, the purpose in phase two was to analyse knowledge on the participants' assumptions for PCA in general and the LSW in particular; to identify the impacts the predefined LSW programme had on each participant. Additionally it was hoped to find out whether LSW, as a part of PCA, has any value in today's services for older adults with ID. Arguments explaining why experts from two other countries than Norway were included in the first phase are dealt with in chapter three.

1.6 Summary of the background and context of the study and further structure of this thesis

The challenges associated with much of the physical, psychological and social ageing process form a basis for the design and methods used in this study. E.g. the earlier onset of the ageing process for a

number of people with ID is one argument for the age limit that is set in this study.

In Norway, the broad conclusion is that we have much of the same history of segregation and discrimination and response to the 'menace' of people with ID as the rest of Europe. People with ID who are 45 years and older have experienced great changes in the services provided by the Norwegian government and in the community's attitudes to their disability. Those people in their 70s and over have experienced World War II and may have dramatic stories to tell in their LSW, as well as from the 50 years people with ID were institutionalised. The municipalities took over the service between 1991 and 1995. The requirement on empowerment emerged in the same period. At this time, we experienced the tendency of the welfare state to standardise services, which has been an issue up to today (Sandvin 1992). A section about performing actors in Norwegian services shows some of these issues related to older people with ID. There is a clarification of this study's terms, definitions, objectives and concepts at the end of this introduction.

The next section (two) is a main section of this thesis and contains theories and data/issues emerging from the literature reviews. It starts with an overview of the three social models (2.1); the medical based individual model, the social model and the relational model. This section explains some of the different trends we find in the UK, Scandinavia and Norway. In 2.2, the headline is valued social role, empowerment and self-determination, which constitutes important themes relevant to older adults with ID in general and especially in the LSW programme that was developed in this study. The same applies to the person centred approach (PCA) (2.3), which framed a number of literature reviews of identity and life story work (2.4).

Theories, models and empirical data that were found in these literature reviews are presented in sections 2.5-2.8. These sections contain relevant reviews of the central phenomena that are explored in this study and constitute the basis for an understanding of the connection between LSW and identity development. They also create the basis for the LSW programme and research tools that were developed with participants' in this study.

Chapter three starts with the philosophical and theoretical perspectives that underpin this study's research design and methods. Interpretative phenomenological analysis (IPA) (3.1.1) and critical realism (3.1.2) are used in combination.

Issues related to people with ID, who in research are defined as vulnerable informants, are discussed in relation to these two philosophical stances. Section 3.2 contains design and research strategies, such as flexible design and participatory action research (3.2.2). The Delphi approach (3.2.1) and pre-interview/intervention and post-interview (3.2.3) are other research strategies in each phase of this study. Ethical considerations are outlined in 3.3. Sampling (3.4), triangulation (3.5) and piloting (3.5.1.1) that providing the designs with validity and reliability, are reviewed. Two sections describe how phase one (3.6) and two (3.7) were carried out. The analytical work is described in 3.8 and the last section of chapter three is a summary.

Chapters four, five and six contain findings for both phases. Experiences collected from the 'LSW experts' (4), the storytellers (5) and the interlocutors (6) are described in main sections containing:

- demographic and contextual information (4.1, 5.1 & 6.1),
- the usefulness and importance of LSW (4.2)

- participants' experiences with structural and practical conditions in the LSW-programme (5.2 & 6.2)
- impact of LSW on service users(4.3)/storytellers (5.3 & 6.3)
- impact of LSW on staff (4.4)/interlocutors (6.4)
- the scope of LSW in Norway, its relevance in today's services to older adults with ID (6.5)

Most of the interpretations and meaning-making (according to IPA) are described in the discussion part (7). Section four, five and six, emphasise the understanding of the participants experiences, while the structure of themes in these sections show the relationships between some of these findings.

The results of the evaluation of the research tool and the LSW programme are not included in this thesis because they are outside of the aim of this study and because inclusion would have resulted in the maximum number of words for a thesis being exceeded.

Chapter seven has mainly three focal points in its discussion; i) the benefits of LSW to the storytellers and the interlocutors, ii) the discussion of findings related to a future 'Norwegian model' of LSW and iii) discussions about current explanatory theories of disability and theories of LSW related to political changes in Norwegian services. Chapter seven ends with reflections on the researcher's role and position in this study and is an introduction to the final conclusions section.

The final chapter eight considers whether the objectives and research questions were met and moves on to examine possible implications from the research findings with a special focus on knowledge transfer.

The conclusion looks in particular at the success and the limitation of the research. The credibility of this study is also considered. This section ends with recommendations for further LSW in Norway.

Data collected in this study made it possible to describe each person more deeply than in section five and six. Data from interviews, weekly reports, films and photo and the researcher's observations from interviews and closing parties, make it possible to describe each person's experience in greater depth. The clear aims and limitations of this thesis means that this kind of analysis had to be set aside for a future study. This study places an emphasis on the development of a life story model. The analyses are therefore based more on critical realism than interpretative phenomenological analyses (IPA), the two methodological stances this study is based on.

Most of the sections end with a summary. There are also 11 appendices to the thesis, an example of the information-leaflets with accessible text being included here. The LSW book that guided the participants through their LSW is not included in the appendices. The templates of consent the participants signed, together with the pre-questionnaires and the interview guides in both phases are however found in the appendices. Appendix 5 contains an example of the scale used in the interviews with both storytellers and their interlocutors. Much additional material (e.g. reflections on the interviews, based on field reports, on the use of NVivo and examples of the analytical work) has been omitted due to space restrictions.

2 Theories about disability, identity and life story work

Society's understanding of people with ID, their valued social role, empowerment and self-determination are important issues in today's services. This, together with life stories and identity, are important factors in the person centred approach (PCA) and constitutes the starting point for literature reviews about personal and identity development in LSW.

The LSW programme was developed to find out the importance and usefulness of LSW. The programme was built on existing LSW models and theories and on today's legislations and policy (PCA). These represent the focus issues in the social, psychological and pedagogical professional fields that are related to people with ID and the services they use.

The following sections provide a brief review of the theories, models and empirical data on society's understanding of people with ID (2.1), empowerment theories (2.2 & 2.3), identity (2.4, 2.5 & 2.6) and life story work (2.4, 2.7 & 2.8).

2.1 Social models related to today's service for people with intellectual disabilities

A basic discussion in most social models revolves around 'who is the owner of the problem? The discussion is about the level of responsibility a person with a disability and/or their families must take and the responsibility that is borne by society.

A second discussion revolves around the influences an individual may have in society and how interactions with society may be used in a beneficial way to assist all parties. These discussions give some indication as to 'who' owns the problem and 'what' the problem is. The discussions also define and give direction to policies, treatments, methods of caring and the variation of services we may find in relation to people with disabilities (Swain et al. 2004).

The best known model in Norway is the *individual, medical model* that emphasises a person's physical or mental deficit. It is used as a central perspective in medicine, psychology and pedagogics and in causal studies, demography and causal treatment (Gjærum and Ellertsen 2002; Kittelsaa 2008; Stubrud 2001). Impairment is, in this model, seen as an individual problem. Changes have to occur 'inside' the person or by using tools that compensate for the impairment. The person owns the problem (Goble 2004; Priestley 2008). One challenge related to this is that definitions and terms about ID have historically fluctuated in response to changes in society and services. The identification, definition and classification of ID in general is less straightforward due to the continuing controversies and confusion in this field about what is an ID, who is intellectually disabled, who is not disabled and how do we know? There is still a lack of standard terminology and definitions (Fuchs, Deshler and Reschly 2004; Keogh 2005; Schroeder et al. 2002).

This also challenges the medical model's use of a number of measurement tools and practice approaches that reveal defects and provide standardised training programs to 'repair' defects. These programs often neglect relational and emotional factors and people are labelled 'patients'. Habilitation and rehabilitations programmes based on this model are mainly institutionalised and segregated programmes

based on the ideal that the service providers do not become emotionally involved in their patients (Stubrud 2001).

It is a requirement in Norway that everyone in services for persons with ID is classified according to the ICD 10. This is a typical measurement tool connected to the medical model (NAKU 2009). This requirement is a contentious issue for older adults with ID. ICD 10 was not developed when they were children and few have been re-diagnosed in adulthood.

It is not always possible to give a clear diagnosis. Some of those who are old today were wrongly institutionalised and developed behavioural problems because of environmental factors. It is quite possible that some may not even have been born with an ID, as for example some of the 'Lebens-born' that were moved to Emma Hjorts Home after the war (Eknes 2000; Fjermeros 2009; Gjærum and Ellertsen 2002; Strømme and Hageberg 2000; Strømme and Valvatne 1998; Stubrud 2001; Walsh 2008).

National and international literature about older adults with ID is significantly weighted by the interest from the medical science community, which is based on a physical and mental health perspective. This means that personalisation, international and national aims about equality, self-determination and autonomy are not emphasised in the literature.

The historically most used model in Norway is the individual medical model. There is, however, another model in use; the *Scandinavian relational model* (also called the GAP-model) which is strongly linked to Norwegian politics, education and service development (Grue 2004).

The main focus in this model is on the individual's impairments, social discrimination and barriers. This model uses the idea of 'disability processes' to describe the relationship between an individual's functional problems and social barriers. The gaps between these are defined as a disability (Sosial- og helsedepartementet 2001). The Scandinavian relational model is compatible with what a research group in IASSID describes as the 'multidimensional model'(Haveman et al. 2009).

Both the medical and the Scandinavian relational model influenced the Norwegian welfare state (which is comparable with the social democratic welfare state), principles on universalism and equality being tested. Laws have been very important as a means to ensure fairness and equality. Welfare politics and rights for people with disabilities are valued more now than before deinstitutionalisation began (Arbeidsdepartementet 2002; Askheim 2008).

National laws give direction to health and social services at different levels and so influence people's lives to various degrees. The *Anti-Discrimination and Accessibility Act* in Norway is a central, general law that local authorities are required to comply with. The requirement of equal rights to information and services is strongly emphasised. So is the individual approach and adaption (Barne-likestillings- og inkluderingsdepartementet 2008). The *Patient Rights Act* is another piece of legislation which has the purpose to promote trust between the service user and the service and to promote social security and the safeguarding of individuality and the user's life, integrity and dignity (Helse- og omsorgsdepartementet 1999).

The *social model* is not well known among practitioners in Norway. This is not easy to explain why. It might be due to the development and success of the welfare state (the Scandinavian model), which emphasises public services and that influenced the way services were developed after World War II.

Mike Oliver's social model, which he developed in 1982 with help from his students, discriminated between impairment e.g. a brain injury and the disability caused by the way people are treated in a society (Oliver 2004). This perspective was well known in Norway in the middle of 1980s when the principal ideas behind the Responsibility Reform (1991) were developed. However despite this, the theory never penetrated so far as to influence local government planning of services in the municipalities.

The social model is based on a collective experience of disablement and not on a personal experience from impairment. This is a frequent conceptual misunderstanding of the model (Oliver 2004).

The social model demonstrates how historical factors reduce the influence of knowledge in this field and emphasises the importance of people's ability to discuss their life stories and the challenges they have encountered (Goodley and Rapley 2001). One contributor claims that *"the focus should include not only a concern for what "we do" and "how we act" (are prevented from doing and acting) as disabled people, but also a concern for "who we are" (are prevented from being), and how we feel and think about ourselves…"* (Thomas 1999: 46). The stories that are told in this thesis in LSW are respected as a source of information and understanding of who the person is. What feelings, thoughts and resources the person has, what stops them from developing to their full potential and why they behave as they do in specific contexts.

One general criticism of the social model has been that it ignores the situation of people with ID (Campbell and Oliver 1996; Dowse 2001; Oliver 1996b; Oliver, Sapey and British Association of Social Workers. 1999). A positive result of this criticism is that the model appears to be more nuanced and complex today than in previous versions (Askheim 2008). One concrete example of this is the social model's contribution to the UNCPRD[2], which emphasises that rights for people with an ID should be equal to those of people with disabilities (UN 2006).

According to Shakespeare there is a need for a toolbox, not a single tool. He says: *"We need to move beyond the polarity of medical and social models. Disabled people do need medical interventions, and do often suffer bodily deficits. But none of us want to be defined by our medical conditions, and the disability movement wants to prioritise environmental and social change, not individual correction."* (p.19). Shakespeare claims that different problems related to service provision, as well as research, need different approaches; *"There is a need for appropriate interventions at the different levels at which people experience the complex phenomenon of disablement."* (Shakespeare 2004: 19).

Shakespeare's views are relevant to this study - a study in which people with ID are respected as the persons they are. Their life stories are important for service providers to gain more understanding of their personality, life situation and life wishes. This can increase the quality of services and service providers feel proud about their work.

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[2] The Convention on the Rights of Persons with Disabilities

The researcher believes that there is a connection between confident, happy service providers and the quality of the service they provide.

The next section outlines the importance of valued social role, empowerment and self-determination as a means in LSW.

2.2 Valued social role, empowerment and self-determination

Social Role Valorization Theory, developed by Wolfensberger in 1983, has been central in Norwegian care development both prior to and after deinstitutionalisation (Askheim 2008; Wolfensberger 1972; Wolfensberger 1983). One description of SRV is: *"the application of what science can tell us about the enablement, establishment, enhancement, maintenance, and/or defence of valued social roles for people."* (Thomas and Wolfensberger 1999: 129).

Defining people as disabled imposes a restriction on them, not simply and randomly on the individual but systematically as a group. People with disability can experience this as discrimination and as being institutionalised by society (Barnes, Mercer and Shakespeare 1999; Oliver 1996). Older adults with ID may have more experiences with discrimination than the younger generation of people with ID, although there are also examples of older adults with ID that do not feel discriminated against. There is, however, not much literature in which the people themselves tell about their experiences and discrimination (Crow 1996; Heia and Westergård 2014; Tidemand-Andersen 2010).

Another relevant point in the social model is *The Disability Pride.* This is a strategy against society's belief about people with disabilities

and the internalized prejudices people can have about them (Crow 1996). We cannot be sure whether people think they are important to society. We cannot also be sure that society in general views people with ID as being important or as being people with potential. LSW may give some answers to this as *"… social oppression and discrimination is only visible through the individual user's experiences and life story…*(Askheim 2008: 172).

A further commitment from the social model, which may be a challenge in LSW, is the 'defence against the service and service providers' and in which the professional power is understood as being a form of oppression (Oliver 1996; Priestley 2005; Söder 2009). Service providers are on one side rated as important, because they have competence. On the other side they are valued as inadequate as they do not understand the experiences people with a disability have (Smith 2009). This last perspective may be said to be an argument that supports the importance of LSW in services for people with disabilities.

A claim made by Wolfensberger supports using interlocutors in LSW. Wolfensberger claims that the only security people with disabilities may have is *"… whatever deep relationship commitments that have been made to them by others, and especially by people who do have competencies and/or resources, including those who are willing to share their last slice of bread with them."* (Wolfensberger 1999a: 500). He believed that the most disabled need an alliance with people with more competence or people with a strong position in society (Askheim 2008; Osburn 1998). Such an alliance may be developed in LSW.

The *empowerment* movement contains a British and an American tradition, even if the difference between them not always is clear (Barnes, Mercer and Shakespeare 1999; Oliver 1996).

The practice of empowerment is built on a set of fundamental principles and has been pervasive in Norwegian policy in services for people with ID since the 1990s.

The Norwegian government describes empowerment as: *"… a goal, a method that is suitable for both the professional and the non-professional and an educational, social and health strategy… Empowerment is to strengthen the power individuals or groups may be in possession of to change and where under the influence of inappropriate relationships… There is a direct connection between empowerment and liberation."* (Translated from Norwegian NOU 1998: 18, Ch. 8.2). This means that asking people about their feeling of liberty indicates how empowered they are. The participant's experiences with liberty and empowerment are integrated in the interviews and as a principle in the LSW programme. It is also integrated by participants' participation in the research process (3.2.2&3.6).

People with ID are expected to be independent and in control of their life conditions and daily life more today than previously. It is a requirement in Norway that health and social services work increases user influence so that they may *"… enhance power and influence to the greatest possible extent/as much as possible, to ultimately be able to make choices."* (Helse- og omsorgsdepartementet 2005: introduction).

Social scientific literature has been criticised because it reduces empowerment to an individual perspective and in that way reduces it to a psychological awareness process. This tradition has not produced many methods, nor any planned or systematic procedures (Andersen et al. 2000; Askheim 2008). The author of this thesis is aware of the different emphases of various empowerment theories with respect to consumer thinking and to citizenship. This is, however, not a discussion that is given priority in this thesis.

The focus in this thesis is on the understanding of empowerment in LSW, self-determination perhaps being the most relevant issue to talk about.

It is important to remember that "*Independence is not linked to the physical or intellectual capacity to take care of oneself without assistance: independence is created by having assistance when and how one requires it."* (Morris 1993: 23). No one performs all tasks themselves, even if they are independent and have control over their lives. They need the help of others. A claim or desire of having control and independence in their own life for people with ID (particularly the oldest generation) will be a challenge. Most need help in order to achieve this.

Self-determination does not depend on a person's IQ. However, the degree of independence and any 'difficult' behaviour is often a challenge and forms the basis for a service provider's decisions on imposing restrictive actions that limit freedom. E.g. the Norwegian legislation on the use of coercion (Helse- og omsorgsdepartementet 2011). Physical disability may also hinder a person from expressing a choice.

There is also a concern about service providers' understanding of self-determination. Some may think of self-determination as something they give to others. However, the law is clear. Every person has the right to self-determination. This right can only be reduced by a legal decision (Helse- og omsorgsdepartementet 1999; Selboe, Bollingmo and Ellingsen 2005).

A White Paper from 2002 concludes that: *"In Norway, there is little tradition for working with self-determination for people with disabilities."* (Arbeidsdepartementet 2002: 8.8). One example are decisions relating to where to live and whom to live with, which are often decided

without the person's consent or involvement. In Norway, about one third (N = 526) have a conflicting relationship and/or are bothered with people they live with (Tøssebro and Lundeby 2002).

'Opportunities' for self-determination are related to peoples' knowledge and the information they are given to make decisions. *The European Disability Strategy 2010-2020* claims there are still major barriers to the accessibility of information for people with disabilities (European Commission 2010). According to Goble *"An example of environmental manipulation aimed at enabling people with intellectual impairments would be the simplification of language and use of alternative symbols and media to convey important information."* (Goble 2004: 44). We find this strategy as a requirement in Norwegian legislation; *"the information should be adapted to individual conditions, such as age, maturity, experience, cultural and linguistic background. The information shall be provided in a considerate way."* (Helse- og omsorgsdepartementet 1999: 3-5). The Act emphasises that the service recipient must understand the things they are participating in. They must also understand the content and meaning of the information they receive (Helse- og omsorgsdepartementet 1999). This is very similar to most ethical regulations about research in the Scandinavian countries (and in most other countries). Accessible information is important in studies where people with ID are participants.

The next section outlines the importance of a person centred approach - an approach that emphasizes a focus on peoples' life stories and identity.

2.3 Person centred approach

The person centred approach (PCA) was developed by the American psychologist Carl R. Rogers (1902-1987). Roger's theory postulates that people with ID are viewed as individuals that are capable of 'self-understanding', of altering their ideas about themselves, basic attitudes and self-directed behaviour when they are together with empathetic, confident, unconditionally positive and genuine service providers who are interested in who they are. This means that service providers must support them in feeling 'free', encourage them to decide what they want, be open to new experiences, be curious, be creative and compassionate (Rogers 1980).

Other aspects often linked to PCA include paying attention to the person's identity, values, lifestyle, norms, experiences, wishes, understanding, relationships, their formal and informal networks and their life stories rather than a 'traditional' one-sided focus on brain damage, disease or disabilities (Brooker 2007; Cambridge and Carnaby 2005; Engedal and Haugen 2004; Harland and Bath 2008; Pörtner 2000).

Norway and the UK debated empowerment/independent living at around the same point in time. Norway however ended up with a more person/user-centred approach in public services. Norway and the UK both developed guidance and regulations on the mandatory use of PCA in services at around the same time. Service providers are often those who are in the best position to strengthen people's ability of self-determination and autonomy. Studies however show that service providers, as a rule, do not follow the regulations they are obliged to comply with (Brevik and Høyland 2007; Cambridge and Carnaby

2005; Helsetilsynet 2006; Jacobsen 2007; Michael, Garner and Garner 2003).

Individual Plans (IP) is a tool that can be used to achieve the objective of adapting services to the users individual needs and wishes (Helse- og omsorgsdepartementet 2009). The regulation on IP is an elaboration of legislation and is an optional right that older adults with ID are granted. Persons who receive longstanding and complex services from various providers have the right to participate in developing his/her own service plan with the service providers. They also have the right to receive accessible information on the process and the contents of the plan (Helsedirektoratet 2010). An IP is perceived as a tool for collaboration. However, only 17 percent of the user-survey in 2012 reported that they had such a plan, even if professionals largely agree that IP is a good tool for customizing and targeting the service (Kosmo 2012).

A literature review on PCA and people with ID was conducted in January 2013 in SveMed[3] +, BIBSYS, AgeLine, AMED, CINAHL, EMBASE, MEDLINE (PubMED) and PSYKHINFO. None of the 7 articles ultimately included in the review were relevant to this study. Scholar.google.no gave 18 articles on PCA. One article was related to old people with ID and experiences with Alzheimer and Down syndrome, but nothing on PCA.

[3] A bibliographic database that contains references to articles from Scandinavian journals in the disciplines of medicine, dentistry, health care, occupational therapy, nursing and physiotherapy.

It was also not possible to find anything in the 'knowledge bank', which The National Institute on ID and Community (Norwegian acronym NAKU) organises.

One relevant Norwegian study was found after the literature review had been completed. It is a qualitative study related to PCA in a nursing home for people with ID (Øverland 2013). The main results of the literature review are similar to those of Professor McCormack when he reviewed the 'person-centredness' in gerontological nursing literature. His conclusion was that: *"… there are very few published research studies in the literature of person-centred practice and even fewer that identify the benefits (or otherwise) of this way of working"* (McCormack 2004: 31).

Researchers in this field report that practice has not followed the good advice provided on PCA (Fugelsnes 2009). It has not been possible in this study to find any other study that explains the gap between PCA policy guidance, governmental objectives and practice on the ground for services for people with ID.

People's life stories and identities are factors in the definition of PCA. The next section outlines the literature reviews conducted in this PhD of LSW, identity and older people with ID. A hypothesis was that LSW may be an appropriate approach to get the service to work in a more individualised way (more PCA) and for older adults with ID to strengthen their feelings of personal strength and their identity/ individuality.

2.4 Literature reviews in life story work and identity in older adults with intellectual disabilities

Literature reviews were conducted in 2007, 2008 and 2010. The emphasis was on the impact of LSW, for example individual development of storytellers and of the listeners (staff) who often help them to carry out a LSW.

The first literature review was conducted in the spring of 2007 in Norwegian, Danish, Swedish and English. Belgian and Dutch literature was not included because of the language difficulties. Key words were: Ageing and identity, identity development and theory, ageing/identity and ID and ageing/life story /development. The search engines were: BIBSYS, SveMed+, AgeLine, AMED, CINAHL, EMBASE, MEDLINE (PubMED) and PSYKHINFO.

Nineteen relevant books/articles were found about life stories and six about identity and ageing. Most were Danish (13) on life history as a pedagogical tool. Identity development as a result of the LSW process was mentioned in some books. But there was no explanation of 'why and how' people changed their identity. Some of the articles on LSW contained ageing and ID; none were on identity development in older adults with ID.

Another structured literature review was conducted in *March 2008* in association with the First Year Report (a requirement of the University of Edinburgh). The main purpose of reviewing identity once more was to gain ideas on how the connection between identity and self/ personal-development can be defined for older adults with ID. It was also conducted to identify relevant literature to develop any research questions.

The search engines used in the first review were used in this review, plus E-journals, JSTOR at the University of Edinburgh and the Learning Disability Quarterly. Potential studies were also identified through on-line research on relevant topics and reviewing references cited in published materials. Literature published prior to 1990 was only included for particularly fundamental theories. The procedure was:

> Criteria: include titles from the 1990s and after in psychology, sociology and philosophy. Exclude titles on discussions between terms and theories.
>
> Keywords: a) Identity and self – b) identity/self and ageing - c) identity/self and ID/ learning disability/ learning difficulties – d) identity/self, ageing and id/ld. Other: institutionalisation of people with ID, personal development and ageing theories.

This study includes people without any memory problems. LSW literature on people with dementia was, however, used because of the similarities in care settings and communication problems.

The relevant search engines at the University of Edinburgh library were mainly used to review publications that were found on bookshelves and electronic Journals. Journals on ID/learning disabilities in English were reviewed using the following procedure:

1) Search words: life story work, identity, ageing, learning disability, participatory research, ethics in life story work and methodology
2) Looking at headlines and key words that were relevant
3) Reading abstracts, include or exclude articles, based on relevance to objectives in this study.

Table 2.1: Results of a literature review on LSW and related themes

Journals	Result	Relevant
British Journal of Learning Disabilities	266	14
Journal of ID Research	124	0
Journal of Applied Research in ID	97	0
Journal of Policy and Practice in ID	32	1

Results from searching on books/bookshelves, terms such as 'learning disability, identity and ageing', gave 52 titles. One was relevant to this study. Most of the publications were found under themes such as psychology and geropsychiatry. A Norwegian journal, Fontene[4], was also reviewed but gave no results.

One more article about LSW in an English project was found and some more literature from Denmark. These were mainly on projects and not research. The literature review therefore came up with very few results. Researchers and therapists that work with people with ID in Norway, Denmark, Sweden, Italy, the US and the UK were therefore contacted for their advice about relevant literature on PCA and LSW. Their answers were that LSW, identity and personal development were topics they had not worked with, neither did they have any suggestions on methods to measure changes in personal development for people with ID.

[4] Fontene is the only Norwegian journal on disability and research in Norway.

Surprisingly few theories on LSW were found in the two structured literature reviews that could explain or illuminate the connection between personal preferences, life stories and impact of LSW: theories which explain why LSW has an impact on people. The result was presented to the panel of the 'First Year Report' and one member suggested a review of scientific literature written by Professor McAdams of the School of Education and Social Policy/The Foley Centre for the Study of Lives at Northwestern University in America.

There is more literature on LSW after 2007 than before. References cited in published reports have been inspected regularly after the first two structural reviews. The literature on this topic is difficult to find principally because terms are used differently. It was difficult to find the right terminology to use in the search engines and I think some literature may have been overlooked as a result of this difficulty.

A new literature review was conducted in *July 2010*. The purpose was to find theories on identity and personal development that are developed through life story research and which could be used in this thesis research design. McAdams came up as a central author and I decided to focus on his publications. McAdams' publications are to be found on following web pages:

i. http://www.sesp.northwestern.edu/profile/?p=46&/DanMcAdams/
ii. http://www.sesp.northwestern.edu/foley/papers/

Based on the sources above, the method of systematically reviewing McAdams' publications was:

1. A review of headlines, abstracts and introductions to find words or meanings about life story, autobiography, narratives,

identity, personal development and ageing. Excluded topics were therapy, peoples' stories or cohorts.

2. Selected publications were reviewed to find relevant topics for questions in phase one or two, or the more general theories for this research.
3. Reference lists in selected publications were reviewed and selected out from the same criteria as '1'. Some grounded theories were found that it was necessary to know more about, which led to the reading of the original literature.

66 titles from 1985 until 2009 were reviewed from McAdams' publishing and 32 titles were found to be relevant to this study. Selected literature contained theories, models and research methods with questionnaires and analyses from different studies.

McAdams' main focus is research on stories from people *without disabilities.* This means that it was difficult to compare McAdams' studies with this study. But his meta-theories are transferable and relevant e.g. the identity model and contributors/theories which he links to this model. This review led to the discovery of a broad theoretical framework for the understanding of LSW in relation to individual development and environmental influences.

The next section outlines some of the theories and concepts that were found in the literature review about identity, identity development and life stories. The lack of theories about personality and identity development related to older adults with ID and LSW led this research in the direction of using theories emerging from research based on information from people *without* disabilities.

McAdams' research and theoretical framework seems appropriate to use as a basis in this study; it may be a way to strengthen the theoretical basis in PCA/LSW for people with ID.

2.5 Identity in a life story perspective

> *"Identity gives us a location in the world and represents the link between us and the society in which we live" (Woodward 1997: 1).*

Ever since the end of the nineteenth century, psychology has looked for explanations of human behaviour through theories of identity development (Saugstad 1998). There are theories that define identity in philosophy, sociology and anthroposophy. More recently we also find discussions on identity in neuroscience (Kircher and David 2003). McAdams' definition of identity, which is pointed out in the introduction of this thesis (1.4), forms a basis for the understanding of identity in this study, consequently also the content in sections 2.5 and 2.6.

2.5.1 An elaboration of the concept of identity

Identity is often defined from a global and at a personal level and we have both a collective and an individual identity (Woodward 1997). Most theorists in this field claim that an exploration of understanding identity starts with the question, 'who am I?' related to 'you', 'us' and 'them', which builds on assumptions about relationship and the world around us. The answers depend on peoples' awareness of uniqueness, social roles and affiliation and give us an answer of how different or similar we are in regard to others.

This variability in human responses, may be analysed from the following three perspectives (Kluckhohn and Murray 1953):

a) Like all others

b) Like some other persons

c) Like no other person

This means that when a) applies to some common features of humans, category b) and c) contain the differences between people (ibid).

R*ole theory* is a variant of identity theory; different roles people are given or put themselves into, are closely related to their various identities (Gustavsson 2012). *Social identity* represents peoples' life and the life they live and is a fundamental part of life which is important for health and wellness (Haslam et al. 2009). Some researchers propose that psychological well-being is influenced by the number of identities, their importance and relationship between them. There are other traditions where professionals look at this as a potential illness and say that too many identities in one and the same person is a weakness (Brook, Garcia and Fleming 2008; Gustavsson 2012). A strong sense of identity makes it easier to see meanings in life and recognize its importance, the opposite can lead to rootlessness and fear of mortality (Buss 2001; Woodward 2002).

There seems to be a discord between the explanation of identity and its relation to other psychological conceptions such as for example self, self-esteem and self-perception. For example, McAdams et.al. and Erikson do not describe identity as being synonymous with the 'self-concept' or even with the common identity-question 'who am I?' (Erikson 1959; McAdams, Josselson and Lieblich 2006). McAdams uses a more technical and delimited definition of identity than what is common in psychology, sociology and everyday parlance (see 1.4 and 2.5).

McAdams claims that individuality and identity are more or less parallels and by working with life stories, we work with our individuality and identities (McAdams 1996).

2.5.2 Theories on identity development

Buss claims that society is not the only source that has formed our identity; there is something in us from the beginning of life that makes us unique and different from everyone else. This is an individuality which is observable as characteristics that differentiate between us and the feeling of uniqueness. The desire of individuality in appearance is tied closely to freedom of choice (Buss 2001).

Erikson's stage-theory confined identity formation to a single psychosocial stage (Erikson 1959), while in McAdams et.al. life story theory, identity is a psychosocial construction - we develop to we die and at different times we might work on special themes or qualities (McAdams, Josselson and Lieblich 2006).

According to Woodward *"Identity is the outcome of a conscious and unconscious process within life as it is experienced"* (Woodward 1997: 304) and Gustavsson says there are two paradigms of identity development (Gustavsson 2012: 29.34 minutes):

Table 2.2: Two paradigms of identity development

continuity experience: *one is the same throughout life*	***mutable continuity:*** *both the same and simultaneously another*
intra-individual identity as successively built up in a psycho-social development (E.H. Erikson)	the dynamic mirror-self (Cooley/Mead)
social identity as a result of existing social categories and group affiliations	tactical self-representation (Goffman)
	floating self-representation/hybridity (Hall)

The identity as a *continuity experience* may be related to the understanding of an ID as a part of a person's stigma (normal or not normal), compensation (functional or not functional) and identity politics. For example, Wolfensberger was most known because he pointed out that devalued[5] people are given a role-identity that confirms and justifies the value a society gives the person (Stangevik 1987; Wolfensberger 1969; Wolfensberger 1972).

The understanding of the identity as a *mutable continuity*, the person with an ID may say:

i) 'When I retired I still had half time job. I wanted to have 100 percent retirement but when I asked about this, my manager thought I was not old enough to have 100 percent retirement' or

[5] People who are valued less important than other people.

ii) ‘I have an ID and I am a normal person’.

The latter example is a case of floating or mixed identity, which is described in studies about people with a light ID (Gustavsson 2012).

2.5.2.1 Identity as an internalised and evolving life story

McAdams’ idea about *identity as an internalised and evolving life story*, ties together a number of theoretical and empirical trends. Identity is for him a life story resonant with a number of important themes in developmental, cognitive, personality and cultural psychology. He claims that by working with our life story, we work with our identities within a narrative frame of stories from the past, present and anticipated futures. These stories confer upon our lives a sense of sameness and continuity and our identity takes form when our stories evolve; *“It is mainly through the psychosocial construction of life stories that modern adults create identity in ‘me’ (-viewed as the self that I construct)”* (McAdams, Josselson and Lieblcih 2001b: 295).

It is less disputed that *narrative identities* are primarily formed by events earlier in life. Accounts of these events and the interpretation of our individual pasts comprise our life story. If we are unable to form or get access to memories of our life story, we have nothing to interpret or narrate that would be sufficient for the formation of self-identity. *“There is a long philosophical tradition, starting with Locke (1690: reprinted 1959), which holds that just such memories form the basis of personal identity”* (Gallagher 2003: 336).

Autobiographical memory is essential for telling a story, consequently also for the identity development. Contributions in this field come mainly from cognitive psychology and researchers have studied how

people encode, store and retrieve information regarding real-life events and personal experiences: *"the relative veridicality of remembered events, the reasons some events are remembered and others forgotten, and the organization of autobiographical knowledge"* (McAdams 2001: 107). According to McAdams the autobiographical memory and narrative understanding have developed so much in emerging adulthood that an identity can emerge (ibid).

Information from autobiographical memories is linked to the individual's personal goals agenda and may be organised in different levels e.g. life time periods, general events event, specific knowledge (McAdams 1985; McAdams 2001). The links between the stories people tell and their emotions, personal strivings and life goals are important in the construction of self-defining memories. This means that a person remembers episodes from the past that are *"vivid, affectively changed, repetitive, linked to other similar memories, and related to an important unresolved theme or enduring concern in an individual's life."* (Singer and Salovey 1993: 13).

The essence of the storytelling, the main reason for establishing a mental condition[6] for storytelling and story comprehension, is the *intentional interaction* with others. It is important for identity formation that we get responses and we are given functions and status. One needs to be seen, understood and accepted to maintain a certain sense of self (Ellingsen, Jacobsen and Nicolaysen 2002).

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[6] A mental condition for storytelling means that the person is able to tell a story from start to the end, with a content that have a meaning.

Studies in developmental psychology found that children from one to two years old had this intentional interaction (McAdams 2001; Stern 1985; Tomasello 2000). Even if these studies are based on research of children without ID, they are used together with findings in this study to suggest a *Life cycle model in life story work* for people with ID (see table 7.2). Some aspects of these theories are relevant to mention in this section where the theories are presented. But they will be discussed further in section 7.3.1.

One of the strongest arguments that are repeatedly being made for the psychological functions of life stories is that it has a primary role in the construction and maintenance of self-identity.

Self-defining memories are representations of vivid and emotional events in one's life and key components of narrative identity (Kerby 1991; McAdams, Josselson and Lieblcih 2001b; McAdams, Josselson and Lieblich 2006; Schafer 1992; Shotter and Gergen 1989; Singer and Salovey 1993). We are then, simply, the assembled stories that we tell about ourselves and the stories that are told about us by others.

In early to middle adulthood it happens that people talk about their *imago*, which McAdams describes as the 'possible self' (McAdams 1996; McAdams, Josselson and Lieblcih 2001b). Imago is a personified motivational trend in the life story, a strong need for the achievement of power, or intimacy such as for example describing myself as 'the loving wife', 'the devoted mother' and so on (McAdams 1985). These are personal identity experiences formed by a process of identification (Hinshelwood 2000) (see also 2.2.3 about generativity).

We also have the power to renegotiate our identity by altering our life stories (Haber 2006). According to McAdams it is common that people in the middle of their lives are revising and reworking their stories, even what remains of their distant past. He claims that this is happening because they have changed their understanding and psychosocial concern as adults. Studies show that after some years people forget what they heard in a specific situation and in midlife people remember events from their adolescence differently from the documented realities of these events (McAdams 2001).

Reconstructive theorists point out the many situations where persons misremember events in ways that shows a strong schema-based processing. An example of this is when we put together a plausible account of the past that has a better coherence for us than the objective re-telling of what actually happened (McAdams, Josselson and Lieblcih 2001b, 2.5.2.2). It seems that most investigators adopt an intermediate position of the two following theories:

1) Memories from recent events are largely reproductive and
2) Memories from more distant events more reconstructive

One issue is to what extent a person's memories can be accurate renditions of what happened in the past. Environmental influences, self-defences and 'memory bumps' influence people's memories. Memory bumps mean that people remember more from some periods of their lifespan, than others. This well-documented phenomenon shows that people remember things better when it happened in the age range of approximately 15 to 25. During this time memories to a greater extent have a richer emotional and motivational content. Researchers explain this phenomenon by all the choices of this period, choice of education, life partner, work etc.

This period also coincides with the time people form their identity (Conrway and Pleydell-Pearce 2000; McAdams 2001; Thorne 2000).

2.5.2.2 Generativity and The Redemptive Self

McAdams, de St. Aubin and other experts in this field support the idea of locating *"generativity in a general fashion, in adulthood"* and define generativity as *"a complex psychosocial construct that can be expressed through societal demand, inner desires, conscious concerns, beliefs, commitments, behaviors, and the overall way in which an adult makes narrative sense of his or her life."* (McAdams and de St. Aubin 1992b:1004).

Society expects that adults take responsibility for the next generation in their roles as parents, teachers, mentors, leaders, organisers, 'creative ritualises' and 'keepers of meaning'. Generativity is in that way prompted by the developmental expectations encoded in cultural demands (Browning 1975; McAdams and de St. Aubin 1992a; Vaillant and Milofsky 1980).

A major source for generativity is an inner desire to be something for others. This is described as a need, instinct or drives that produce desire for a symbolic immortality, to be needed by others and be of important use to other people. McAdams et al, call this the constructing legacies that live on after the person's death (McAdams and de St. Aubin 1992a).

The *redemptive self* is when an adult expresses concern for and commitment to promoting the well-being of future generations.

Highly generative adults have more redemption sequences in their stories, which is especially characteristic of the narrative identities constructed by highly generative adults (McAdams and Pals 2007).

A redemptive sequence in a person's story expresses a bad or affectively negative scene, for example abuse, but which they then give a positive outcome or interpretation in the stories they tell. The negative experience is saved, salvaged or redeemed by a positive turn of events, or by the person's conclusion that some redemptive meaning emerged (McAdams and Pals 2007; Pals 2006). Studies in this field have found that persons who faced difficult life experiences, constructed stories that suggested that they had learnt lessons, gained insight or experienced positive psychological growth as a result (ibid). These studies underline the importance of fully expressing and acknowledging the strong negative emotions with respect to a negative life scene and constructing a narrative ending or meaning for the scene that affirms personal growth (Pals 2006).

2.5.3 Identity development in people with intellectual disabilities

Based on theories about identity and review of studies about people with ID, there still remains the question about whether or not they develop an identity in the same way as people without a disability do. If they do not, is the reason reduced cognitive ability (a biological influence) or the expectations other people have to them (a psychosocial influence)?

Baron et.al. (1999) claim it is important to study people with ID in terms of theories and ideas about transitions in addition to identity,

because of their impact on strategies in lifelong learning and other political strategies related to public services.

In addition they represent the abnormality which is important to understand the nature of identity in general (Baron, Riddell and Wilson 1999).

The basic understanding of motivated action and understanding, is referred to in the empirical literature as *the theory of mind*. At the age of three and four years the ability to interpret the actions of others and oneself starts. This skill is basic for an effective social interaction (Baron-Choen 1995; McAdams 2001; Wellmann 1993). Some people with ID have problems with interpreting social actions and some of them learn this much later than from the age of three or four. Some of them might never learn it (Gjærum and Ellertsen 2002). Especially people with autism find mind reading difficult. The lack of understanding applies to the self as well and results in a disturbing dysfunction to formulate and convey sensible narratives of the self (Bruner 1994; McAdams 2001; Sacks 1995).

It is important that children are given a free role for experimentation to find their 'niche' and to make a bridge from these discoveries over to their life (McAdams, Josselson and Lieblcih 2001b). This is not easy for persons with ID that are often identified by their diagnosis rather than by their name, status, personality, gender, age, ethnicity etc. (Gray and Ridden 1999). A case study from Baron et.al. (1999) is one of the few that describes identity development, or lack of such, among three adult people with ID. It was expected to find significantly differentiated biographies and identities, but the similarities between the participants were striking. None had formed an intimate personal relationship and all three were said to have 'learning difficulties' as

the master category of their identities. None of the three people studied referred to themselves as having ID; at the same time they had few opportunities to contest this as a master identity because of the repertoires from which they had chosen their identity. Baron et al. found that the three lives they had studied were characterised by the degree to which identities were *"imposed on them by a series of others, rather than being playfully constructed by the actors themselves."* (Baron, Riddell and Wilson 1999: 493). This was reinforced by the discourses of the law, social work, education and the family, which actually imposed their master identity on them (ibid). The general lack of independence which most people with ID experience makes it difficult to find what others discover as their 'niche' influence, their identity.

Two more recent studies in Sweden and in France, examined the self-expectations and self-identifications among people with ID. The researchers found that they were influenced by the expectations others had of them as a) a service user going to a role as service recipient (learnt passivity) or b) a person such as others in addition to a service user (goes into more common roles with ambitions). The researchers' concluded that the role they took influenced how they were categorised as prodigals or winners (Gustavsson 2012).

It is often researchers without disability who define the identity and history of people with ID and compare it to the current life situation. Groups whose lives have been excluded from mainstream history, have recognised the importance of discovering their own history e.g. as a group to challenge the stereotyped assumptions about who people with ID were and what their lives are like.

In the book *Am I an adolescent or do I have Down Syndrome*? (Translated from Norwegian) (Tidemand-Andersen 2010) the author investigates how young people with ID work together in a group and give each other responses they otherwise would get from other classmates if they not had an ID. These stories about how people with ID support each other's development are relatively new knowledge in Norwegian literature (ibid).

In considering the purpose of people with ID recollecting and sharing their histories, the editors of the book *Forgotten Lives* argued that the study of history may contribute to a sense of identity because parts of personal identity is a sense of our own history. According to Atkinson a sense of the history of a group to which we belong, whether we like it or not, by virtue of our label, are important for a sense of *group identity* (Atkinson, Jackson and Walmsley 1997).

Dorothy Atkinson has helped people with ID to write their stories in the way they remember them and want to portray themselves. The book *Forgotten Lives* is one example where the authors told their stories in order to make a change in living conditions for people with ID. In 1990s, when this book was written there were many people with ID who still lived in long stay hospitals and shared 'homes' (Atkinson, Jackson and Walmsley 1997).

In another project, *Our Journey through Time,* five young people with IDs explored the history of people similar to themselves. The project taught them what life had been as late as 30 years earlier and they concluded that it was very different from their own lives; they had more choice, more freedom and more opportunities. The research process and the conclusions these people came up with is a way to consider their own life and group identity (Bentley et al. 2011).

People with ID are generally not mentioned in theories about generativity. Neither is the generativity prompted by expectations encoded in cultural demand for people with ID.

The explanation may be that their social roles seldom are similar to those of other people in society; few of them are parents, teachers, organisers, leaders, mentors and keepers of meanings. Despite of this, I believe generativity is relevant in LSW for people with ID and something the service providers who act as interlocutors must consider.

One example of 'generativity' and 'the redemptive self' among people with ID is the story from John Davies, who had cancer. When he knew he was dying, it became important for him to tell his story and in that way give advice to others, how they should take care of themselves so as avoid having his fate (Tuffrey-Wijne and Davies 2007)

Research has shown that persons with ID tend to emphasise different things in their narratives than those without ID (Van Puyenbroeck 2006; Van Puyenbroeck and Maes 2005). Most of them have grown up in a very different way from other people and might have problems with remembering due to brain damage or because it simply is too painful to remember parts of their lives (Atkinson 2004; Lesseliers, Van Hove and Vandevelde 2009). Other studies show an amazing capacity to remember, often better than staff (Thorsen 2005).

According to Haber one threat to keeping one's identity, is the rapid pace of change in society, combined with a negative stereotype of ageing (Haber 2006).

Older adults in this study have experienced many changes since they first received services because of their disability. A number of older adults with ID have long experience of exclusion and ageism, or the newer term ‘intersectionalism’, which describes the interactions between multiple systems of oppression and discrimination (Nelson 2002; Quadagno 2008).

Institutionalisation seems to involve a risk of declining quality of life, subsequent mental problems and the loss of identity. Many of them who grow up in an institution will have life histories that affect them later in life, both regarding their picture of themselves and their perception of security and predictability (1.2). In many ways they were hindered by the institutional regime in their attempt to find their own identity through decisions about work, relationship, education, activity and travelling (Eknes 2000; Johnson and Traustadóttir 2005; Stubrud 2001; Tøssebro 1996; Tøssebro and Lundeby 2002).

Some people with ID, who were sent to institutions in their childhood (2.2) and lost contact with their family, may have more problems than others to remember their family. Some say that they do not remember their mother’s and father’s names, while other says they were both ostracised and forgotten by their family. The idea of ‘family’ that for most people is the safe anchorage point, becomes for others a very unsafe anchor that often is related to shame, because they have forgotten both the family names and the family relationships (Thorsen 2005).

The lack of studies on long-term-effects as well as those that combine memory, identity and history makes it difficult to say something more conclusive about this period of the lives to people with ID (Bjornsdottir et al. 2008).

It seems that a focus on personal development is not a common trend in services for older adults with ID. Nor is the development of knowledge that can inform and help them to a positive perceptions about themselves, based on own resources and desires. It seems more usual to focus on decline and illness when people grow older.

The perspective is interesting related to older adults with ID, how do they describe themselves? As far as the literature review in this study shows, this is not a typical topic in the literature about people with ID.

In particular, there is a lack of knowledge about the elderly person's experiences of social identity and the role psychological environments play in identity development or a change in identity from a child, to an adult and to an old person. Consequently there is little knowledge about how older adults with disabilities define and develop their own identity (Baron, Riddell and Wilson 1999; Thorsen and Hegna Myrvang 2008).

The next section outlines some of the findings in literature produced by McAdams, which is a central contributor in this study. The lack of theories about personality and identity development related to older adults with ID and LSW, led this research in the direction of using theories emerging from research based on information from people *without* disabilities. McAdams' research and theoretical framework seems appropriate to use as a basis in this study; it may be a way to strengthen the theoretical basis in PCA/LSW for people with ID.

2.6 A life story model of identity

Since the 1980's McAdams has developed life story models and he may be said to be one of the most experienced researchers in this field. His publications have a wide view and include both a psychological and a social focus.

Part of this study is based on theories in personality psychology that more or less, indirectly or directly, are used in McAdams' life story model of identity (1985, 2001). The life story model of identity from McAdams and theories he bases his model on are used as a foundation without explicitly describing or discussing them.

So far, there is no broad theory or conceptual system that integrates all the useful and valid personality constructs. But they may be arranged and examined according to some broad conceptual domains or levels (Hooker and McAdams 2003; McAdams and Pals 2007). As shown in table 2.3, personal identity may be viewed from these different standpoints of levels and focuses.

Table 2.3: The life story model of identity

structural components	parallel process constructs
Level 1: TRAITS global disposition signatures for behaviour across situations and over time. (The Big Five)	STATES can note dynamic change or constant possibility of changes (in mood, fatigue, hunger, anxiety)
Level 2: CHARACTERISTIC ADAPTATION/ PERSONAL ACTION CONSTRUCTS (PAC) goals, striving, developmental tasks, defences, values, beliefs, motives; the doings of the personality (Contextualized).	SELF-REGULATION self-efficacy and outcome expectancy
Level 3: LIFE STORY understanding of the self: reconstruct the past and anticipate the future in order to find sense of meaning, unity and purposes. (expectation for the purpose of finding a form of meaning, wholeness and purpose in life)	SELF-NARRATION storytelling changes according to social context, different memories may align with current realities

(A summary developed from literature reviewed of Hooker and McAdams 2003; McAdams 1996; McAdams 1995; McAdams 2001; McAdams and Pals 2007).

Each level has unique discourses for understanding the individual and also specifies its own methodological operations. The model is hierarchical in the sense that the second and third levels build on the first level.

Each level develops in different periods of the humans' lifespan; 'Traits' develop as infant; the 'characteristic adaption/personal action constructs (PAC)' and 'the life story' develop in late childhood and adolescence (Hooker and McAdams 2003; McAdams 1996; McAdams, Josselson and Lieblcih 2001b; McAdams 1995).

By looking at peoples' traits we find a number of similarities, which build on the empirical facts that traits are biologically and genetically influenced. At this level, the 'Big Five' is used to describe and characterise similarities and differences between people (2.6.1).

We find fewer similarities in peoples' particular goals and development tasks because characteristic adaption (or PAC) depends on context and adaption. This level represents similarities in persons that belong to the same society or are close to each other, for example in the same family or the same interest group.

A person's life story is the only part of a human being that is uniquely created and is increasingly different between people (Hooker and McAdams 2003). Traits and PAC 'speak' directly to the issue of identity. In life stories we find the meaning of a person's life and we may get to know how the person's psychosocial world is arranged to provide a life with a modicum of unity and purpose(Giddens 1991; McAdams 2008). This is according to McAdam's definition of identity (4.1). Some more explanations of these three factors that together form and define people's individuality/identity are outlined in further sections.

2.6.1 Personal traits

Researchers do not agree which mechanisms change or maintain traits, but one suggestion is the history and life events. The definition of dispositional traits is:

> *"Broad dimensions of psychological individuality that describe assumedly internal, stable, and global individual differences in behaviour, thought, and feeling. Traits account for consistency in individual functioning across different situations and over time."* (McAdams and Pals 2007: 7).

The Big Five taxonomy resides at level one in the model above (table 2.3) and provides a general, comparative and non-conditional dispositional signature for a person. Examples of personal traits are (McAdams 1996):

- Neuroticism
- Extraversion
- Openness to experiences
- Agreeableness
- Conscientiousness

The most validated construct in personality psychology is probably *extraversion*, which refers to how outgoing and spontaneous, sociable and energetic a person generally is. The opposite is the *introvert* which in general is: retiring, quiet, deliberate and withdrawn (McAdams and Pals 2007).

Personal traits is proclaimed to be one domain that will not change in later life (McAdams and Pals 2007). Research shows that traits in later life may be predicative for important outcomes such as social support, psychological wellbeing, self-rated health and functional status.

Extravert people report a greater level of positive emotion in everyday life than introverts, who tend to report greater levels of negative

emotions in everyday life. These indications are mainly reported from studies that use extraversion scales correlated with reports of mood and affect aggregated across situations and over time (McAdams and Pals 2007).

Hans J. Eysenck was influenced by behaviourist theories on learning and conditioning and expanded the extraversion theory to include a cortical explanation of differences in arousal levels between the extrovert and introvert types of personality. One interesting result in his study was that introverts are more sensitive to any kind of stimulation: they tolerate relatively little social stimulation before they get an optimal level of arousal. Beyond this level they start to withdraw to reduce the arousal (McAdams and Pals 2007). In contrast, an extrovert person is 'stimulus hungry'.

An extrovert person will seek social stimuli and may have a huge social network, while an introvert person e.g. might want to do LSW at home and may ask other people to collect pictures and stories about their life. An extrovert person may want to visit places and people from 'old days', while an introvert person may like to visit the same room to do LSW every time.

Hans J. Eysenck's theory seems useful for understanding the situation of introvert persons with ID especially. Additionally some people may have communication difficulties that influence their ability to avoid situations with too many stimuli. Over time this tendency may lead people to develop self-harming strategies as a way to get out of situations when 'it all gets too much'. When introverted persons do LSW, it may be important that the interlocutor knows this and so can take care of the persons' need for minimum levels of stimulus.

Criticism of Eysenck´s arousal theory and the developing of a new system for studying the brain, has resulted in a shift over to the concept of *Behavioral Approach System (BAS)*, which today is more common: *"BAS refer to a functional system in the brain and is hypothesized to govern positive approach behaviors in response to incentives." (McAdams and Pals 2007:11).*

In *development theory* it is stated that although cognitive dysfunction is important, it is not sufficient to explain the performance and behaviour of people. Factors such as motivation and the development of personality characteristics and traits are also likely to be important in making sense of the overall presentation of an individual. The psychological developmental model suggests that life experiences and socialisation are important factors in developing personality traits and styles (Zigler and Bennett Gates 1999). In the light of this we may assume that typical traits in people with ID may be changed when they grow up in an institution and had to fit into an institutional life. Also the fact that most people with ID have qualitatively different life experiences than others without ID, is relevant in this case.

2.6.2 Characteristic adaptations/Personal Action Constructs

Characteristic adaptations/Personal Action Constructs (PAC) refers to the motivational, social-cognitive and developmental concerns and it differs from the dispositional traits in relation to context. A definition of characteristic adaption is:

> *"… particular features of psychological individuality that describe personal adaptations to motivational, social-cognitive, and developmental challenges and tasks. Characteristic adaptations are usually contextualized in time, place, situation or social role."* (McAdams and Pals 2007:7).

Research in social motives for power and intimacy have found an important link to people's life stories (McAdams 1980; McAdams 2001; Winter 1973). When people have a *high intimacy motivation* they emphasise themes of friendship, love, dialogue, caring for others and they often use an analytic and differentiated style when they tell their life stories. People who have a *high power motivation* in contrast, tell about self-mastery, status, victories, achievements, responsibilities and empowerment in self-defining memories (McAdams 1980; McAdams 2001).

The *ego development theory*, developed by Jane Loevinger (Loevinger 1976-1978), is central in personality psychology and belongs to the level of personality construct. Loevinger built her theory from cognitive-developmental psychology and interpersonal psychodynamic psychology and perceives *"ego development as the sequence of changes that plays itself out in the way people make sense of themselves and the world over the human life course"*(McAdams and Pals 2007:12). This theory proposes a link between ego-development and individual differences in the structural part of life stories (McAdams, Josselson and Lieblcih 2001b). People with a relatively highly developed ego have a more nuanced and individualistic framework for making sense out of their subjective experiences. They tend to deny that they have gone through some personal life crises. They also employ a greater narrative complexity than those with low ego-development, who tend to view experiences more in black and white and in conformal terms (Helson and Roberts 1994; Loevinger 1976; McAdams 1985; McAdams 2001; Pillemer 1998). This study does not analyse people's life stories, so motivation and ego theories are not taken further.

We do not know how and if characteristic adaptation increases or decreases personal well-being in general. By reflecting on this in connection with PCA and service users' personal goals in their IP, we have to evaluate service users' empowerment and involvement in planning processes. We also have to consider the use of plans and methods in terms of what impacts these have on expectations of the individual and the staff. An adverse development for users and the service may be explained with a lack of focus on users, their personal development and perceived quality of life.

Studies about self-defining memories among people without ID show that when memories are relevant to a person's attainment of their life goals, there is a greater level of positive affect connected to their memories (McAdams 2001; Stern 1985; Tomasello 2000). Based on this statement, it might be more difficult for older adults with ID, who have had to adapt to an institutionalised life, finding positive memories from their past and connecting them to present life goals their ability to cope and the ability to face challenges in life.

2.6.3 Life stories

The stories people tell, belong to the third level of the personality construct model. This level contains plots, characters, images, themes and scenes that are central to a person's understanding of who he or she is, was and may be in the future (Hooker and McAdams 2003).

Even if some classical early theories on personality (Adler (1927) 1946; Murray 1938), intimated that life stories were important, Tomkins (Tomkins 1979: Script theory) and McAdams (1985, 1993, 1996: life story model of identity) were the first to take seriously the

stories people told about themselves as features of their personality. The general idea of narratives has proved a new basic metaphor for the field of psychology as a whole. Contemporary psychologists investigate stories of individual lives, stories of intimate relationships, family stories etc. (McAdams 2001).

Life stories play a crucial role in almost every human activity, it dominates human discourse and is fundamental to the cultural processes that organize and structure human behaviour and experience. Life stories are also fundamental to human reality and the understanding of human experience. They offer important ways to encode human truth and experience and, in turn, share knowledge and insights with others. According to the psychologist, Jerome Bruner, life stories are *"… one of the crowning achievements of human development"* (Bruner 1990: 67).

When people talk about their life history and the meaning their stories had in their life, they may find 'a red thread'; they discover how events are connected and build upon each other. In telling a story, they participate in the act of constructing themselves and constructing their own world. People reveal tacit knowledge about themselves and tacit knowledge of the world in which they participate.

McAdams describes the perfect unity and purpose in life, more as an ideal and something people seek and try to achieve, than as some clear ideas people use actively in their daily life (McAdams 2001). Antonovsky uses the term 'a sense of coherence' when people see the meaning and the sense of the world (Antonovsky 1987). A sense of coherence may contribute to good health, because people understand the meaning and context of what is happening and consequently are better equipped to deal with things in their lives. Likewise, LSW may

illustrate how older adults gain a deeper acceptance and understanding of what has happened to them and that they are more likely to reflect on past experiences and emotional stress (Antonovsky 1987; Eriksson and Lindström 2007; Hamilton and Atkinson 2009; Lindström and Eriksson 2005).

In spite of this, it is not common to find personality theories related to LSW. Nor in the literature about PCA is the personality theory often found. This is quite strange, also because the founder of PCA, Carl R. Rogers, was a psychotherapist with a unique understanding of personality and human relationships (Pörtner 2000).

The next section contains the results of reviews about LSW as an intervention to study experiences and possible changes among the storytellers in LSW as well as their interlocutors.

2.7 Life story work

Since 1990s an effort to write, interpret and disseminate people's life stories has developed in interdisciplinary social science, with special attention on people who represent parts of the population who historically have been ignored or oppressed (McAdams 2001).

LSW is well documented in the UK, Netherlands and Belgium, Australia and Eastern Europe, - and it has been incorporated in the UK's Adoption legislation (Levesque 2012; Meininger 2005). Despite this, theories related to the life review perspective have received scant attention in the literature (Haber 2006).

2.7.1 Definitions and delimitations

Life story work (LSW) and related terminologies are used by different professional disciplines e.g. social work, pedagogy, psychotherapy and medicine (Atkinson, Jackson and Walmsley 1997). It differs from psychotherapy or other psychological treatments that aims to treat behavioural or mental problems (Haber 2006, see also 7.2.4). LSW is often used as a general evaluation of one's own life that forms a basis for personal reflections. Despite this, there is a remarkable lack of terms, definitions and clarity in the field (Haber 2006; Meininger 2005).

Life review and *reminiscence* are the most common used terms in the literature (Haber 2006). These concepts have a wide variety of definitions, but commonly they refer to the recall of memories, events, things, or places located backwards in time, often in a systematic process. (Butler 1963; Gibson et al. 2004; Haber 2006; Moos and Bjorn 2006). The term life review is not used in this study because it often refers to *"a time-limited psychosocial intervention specifically designed for older adults people…"* (Haight, Michel and Hendrix 2000: 159), often with a therapeutic purpose to help people coping with depression, guilt, conflicts etc.

A life review is more likely to be evaluative where people ask about the meaning of their life, while life history and reminiscence in contrast are more focused on detail of events in a descriptive way (Haber 2006; Haight, Michel and Hendrix 2000). While LSW is more on a structural level (see definition in 1.1), life stories and narratives are more on the individual and personal level (Bruce and Schweitzer 2008).

The most important matter in LSW is the personal history (Svennen 2006; Van Puyenbroeck and Maes 2006). One definition of *life stories* used in this thesis is:

> *"Internalized and evolving narratives of the self that people construct to integrate the past, present, and future and provide life with some sense of unity, purpose, and meaning. Life stories address the problems of identity and integration in personality-problems especially characteristic of modern adulthood."* (McAdams and Pals 2007: 7).

In their definition of life stories McAdams and Pals (2007) use the concept *narrative*, which means to know and to tell, defined as:

> *"…discourses with a clear sequential order that connect events in a meaningful way for a definite audience and thus offer insights about the world and/or people's experiences of it"* (Hinchman and Hinchman 1997: xvi).

Narratives are stories people construct to make sense of their experiences (Bruce and Schweitzer 2008). First-order narratives, or personal testimonies may be understood as constructs of individual identities (Elliott 2005) that may *"occur spontaneously in everyday life, during the course of normal interactions"* (ibid: 12).

The idea of *oral stories* are often less controlled and more dynamic than an *autobiography***,** which is a written account of life in first person about memories from one's life story (Bruce and Schweitzer 2008; Fossland and Thorsen 2010; Thorsen and Hegna Myrvang 2008). They both differ from a *biography* which often describes an account of a person's life compiled by another person (Bruce and Schweitzer 2008).

The distinction between life review, life history, reminiscence and LSW (as it is used in this study) may be visualised, as the table below shows:

Table 2.4: Differences between reminiscence, life history, life review and life story work in relation to time

	past	present	future
reminiscence/life history	X		
life review	X	X	
life story work	X	X	X

2.7.2 The history and prevalence of life story work

LSW as a concept dates back to at least the 1960s, possibly even earlier (Aust 1981). In 1963 Robert Butler wrote an article[7] that became a major impetus in the field. He made a distinction between reminiscence and life review and argued that reminiscence was universal, a statement that was controversial among other professionals at that time (Haber 2006). Since the 1980s, the social sciences have witnessed a strong upsurge of interest in narratives and life stories as they affect human lives and social relationships (Hussain and Raczka 1997).

[7] The Life Review: An Interpretation of Reminiscence in the Aged

From the early 1980s onward, LSW was discussed in academia as being related to children in foster care and adoption (Ryan and Walker 2007) and in the same period Maureen Oswin (UK) published a pioneering work named *Am I allowed to cry?* This was a study of bereavement amongst people with learning difficulties who had 'lost' their life story and identity (Oswin 1991).

In the UK Charlie Murphy updated a publication about the child care field in 1993 and ended up by doing research which resulted in a publication called *It started with a sea shell (Murphy 2011)*.

In 1994 *The Association of Personal Historians* (APH in USA) was founded and one year later an international biannual conference was launched, called *The Reminiscence and Life review Conference*. This was the start of an increasing number of persons to begin work with life reviews (audio tapes, written materials, CD-ROMs etc.) (Haber 2006). Right now Dr Barbara Haight, Professor Emeritus at the College of Nursing, Medical University of South Carolina, is probably the most influential author in the life review field in the USA.

As in the USA, a 'Life Story Steering Group' was started in the UK in 2003 from an initiative of Ken Holth and other professionals. It was the same year as his wife Alice went into a nursing home and he wanted the staff to know her background. *"The communication was done through the life story"* he says in an interview with Polly Kaiser (Kaiser 2008). In the interview Holth recounts one example where his wife wanted to go to bed with her clothes on and explains this with stories from World War II, where people used to sleep with clothes on to get up quickly and go to the shelter. He was sure that she got better care because they knew the reason for some of the peculiarities in her behaviour. Alice's story built relationships with the staff, who felt

safer and more relaxed because they knew about her likes and her dislikes. Holth says that everyone should do LSW and especially mentions the importance for people with ID. His arguments for the LSW are (Kaiser 2008):

> *"We all have a great amount of experience we can draw on - we have our struggles and hardships, our strengths and hopes that endure part of our story.*
>
> *Telling your life story will help to identify the core values and beliefs that you hold."*

In some European countries LSW is used with children as young as one month and more, with amazing results (Eliacheff 1994; Lier and Gammeltoft 2001). LSW has also been used in services for people close to death to create a distraction from thoughts of death for a while (Eriksson 2007; Rasmussen 2005).

The link between loss, bereavement, grief and how to cope with these feelings by using LSW, was a concern the Danish pedagogue Susanne Hollund took up in 1985 when she started to be interested in her clients' life stories (Hollund 2007b). Susanne has been active in helping people with ID to develop their life stories, especially those with severe and profound ID. She shares her knowledge and experiences in the webpage: www.shollund.dk (Hollund 2007a).

Murphy found that whilst 99 percent of the people he met in his training sessions about LSW said it was a fantastic idea, only 5 percent actually did something about it (Murphy 2011). To compare, a Danish literature study they found that among 28 studies from 1990 to 2003, only one study had a well thought out plan for how the LSW should be used on a daily basis and as a tool to provide better services and more individual caring (Moos and Bjorn 2006).

In 2010, the National Life Story Network in the UK commented that LSW still lacks a repository for sharing knowledge and best practice for individuals, families/carers and front line staff (The National Life Story Network Steering Group 2010). The same may be said in Norway; there is a lack of knowledge about places or local communities in Norway that are using LSW on a 'daily basis'. Probably there are very few. No such projects have been discovered through the Norwegian literature review in this study. I believe there are LSW projects in nursing homes, which is not documented. The same may be said about services for older adults with ID.

In 2007 and 2009 the Norwegian National Advisory Unit on Ageing and Health arranged LSW courses for older adults with ID and later on for the staff. Both staff and people with ID were enthusiastic to the LSW but reports from practise shows that most of them have not followed up the LSW on daily basis.

The only Norwegian books that are published about life stories, contain analysis of life stories of people with ID (Fossland and Thorsen 2010; Thorsen 2005; Thorsen and Hegna Myrvang 2008). Additionally, there are two practical books about LSW, named *Min historie/*My history (Olsen et al. 1994) and *Dagene mine*/My days (Andersen et al. 2008). None are with accessible text (see 2.8.1).

A conclusion that can be drawn is that despite its value, LSW is not often used to its full potential. According to Van Puyenbroeck there are needs for future research in this field, which are (Van Puyenbroeck 2006):

- More knowledge about the methods and usefulness of LSW
- Clear descriptions of methods that are related to the objectives

- Documentation of the benefit that LSW has for many people, including parents and other relations
- Research on people's ability to carry out a liberating examination of themselves and their own self-image

2.7.3 Life story work, other professional fields and orientations

LSW, psychological therapy and mapping-systems often have similarities, but also different perspectives that may be assessed by looking at the purpose and the process of empowerment (2.2). Empowerment represents a methodology, associated with feminism and processes of self-consciousness, which is most related to processes in LSW, or at least the LSW programme developed in this study. Below, table 2.5 shows the distinction between psychological therapies, mapping-systems in health and social services and LSW (table 2.5 and 2.6 are based on summaries from Iversholt et al. 2003).

Table 2.5: The distinction between psychological therapies and mapping-systems in health and social services and life story work

perspectives:	purpose of asking about a person's life story	the process of empowerment
psychological therapy	assessment and evaluation of a problem	the person is helped to cope with his life-situation, feelings and behaviour
mapping systems	collect information to provide good service in accordance with applicable laws, administrative/ economic framework	staff holds the process and can use the information to create a social environment to support the process of empowerment
LSW	increase self-consciousness about various conditions and connections in own life make something visible or audible to present their own life stories	the person/service recipient holds the process; integrity and power in the work with own stories, defines and decides the process and the outcome of the process

The main difference is that mapping-systems are administered by professionals and are a requirement in health and social services.

By contrast, LSW may be administered and owned by the storyteller and so is more related to personal and private experiences and perspectives (see examples in 2.8.1). When professionals ask about the service user's personal and private life, they need to be aware of why they do it, how they do it and with what purpose they do it. When professionals manage the LSW programme, it may be used more as a pedagogical tool and not as a subjective value for the storytellers, see table 2.6.

Table 2.6: LSW approaches as a formal requirement or as a personal perspective with a subjective value for the storyteller

*a formal requirement; a **categorised access** to life stories*	*from a personal perspective; a **value-oriented access** to life stories: LSW is initiated because of its subjective value*
focus on the problematic stories: professionals collect information and interpret it in a medically, pedagogical, psychological and social context/framework of understanding	*focus on subjective importance in a life story context:* - the service user is the narrator and the stories are explored when they are told - any interpretations are done by the service user, with help from an interlocutor or by the interlocutor with an understanding from the service user's perspective
categorising: the professionals define the service user's problem	*Pedagogical/psychological self-reflection:* the professionals are inspired by the service users' life stories to reflect over the health, social-psychological and pedagogical environment, in addition to professionals' tasks and roles in the service
describing pedagogical objectives: the professionals defining objectives and methods for the service.	*establishment of a cooperation process:* the objectives and the process of LSW are decided in cooperation between service users and professionals, which can be a dilemma filled process

The next sections contain a review of theories and methods as a basis for the LSW programme that was developed in this study.

2.8 Central theories and models in LSW

The following sections contain descriptions of relevant, theoretical and practical topics about LSW. Literature, films and internet pages about LSW were analysed and structured with a focus on: contributors, participants, objectives, recruitment, time spent,

the degree of empowerment, the use of memorabilia, theories directly related to practice, end-products that presents life stories, facilitators/ interlocutors and eventually pre-training.

2.8.1 Models of life story work

LSW can provide access to life stories in a formal setting. For example, life stories are often used as a tool in psychotherapy. Our life stories are however, first and foremost, a private perspective and have a subjective value (see table 2.6 above).Some examples of these ways of accessing people's life stories are described below.

One example of a 'categorised' access to people's life stories is from *Barbara Haight* (USA) and her colleagues. They emphasise a structured form of life review (2.7.1), whereby the whole life story from childhood to present age is reviewed in a systematic manner utilising Erikson's 8 Stages Theory (Erikson 1959; Erikson 1963). According to Haight et.al. the reason for reviewing and looking back is to reframe and reconcile the memory of a stage that was not successfully completed at the proper time in the past. She studied elderly people (without ID) in various places and she frames life review as an interpersonal, therapeutic process whereby a 'reviewer' speaks with a 'therapeutic listener' (interviewer) in a structured format, over a series of 1-2 hour sessions in approximately 8 weeks.

According to Haight this process is ’therapeutic’ in the sense of promoting personal integration, understanding and emotional well-being. But it is not ‘clinical’ in nature. A life review is valued as powerful and meaningful for what Haight’s denotes as ‘personal enrichment’, rather than for clinical/ psychotherapeutic reasons (Haight and Haight 2007).

Another example of categorised access to LSW is by *Feryad Hussain and Roman Razka* (UK). They worked with people with ID and their objective was *“to use LSW as a means of easing the transition for people when moving from long-stay hospitals into community residential homes”* to give them an *“opportunity to deal with the loss and bereavement of their previous lifestyle.”* (Hussain and Raczka 1997: 73). The authors developed a *Life Story Pack* consisting of sections such as *“Family, Relationships, Education, Long-Stay Hospitals, Community Homes, Leisure Activities, etc.”* (p.74). The end-product of LSW was life story books and collection-boxes with items (ibid).

Susanne Hollund (DK) uses both an initiated approach to access peoples’ life stories and a categorical access - as a pedagogical tool. She speaks about the subjective value of LSW at the same time as she emphasises the value of LSW as a pedagogical tool for changing peoples’ behaviour. Some of the people with ID she works with have poor language skills, which makes a difference to the degree of access to peoples’ life stories. The degree of user-empowerment does not seem so clear when the professionals make a ‘user’s professional history’, based on journals and reports from different services. When staff facilitate the users’ private history, the users have more empowerment, but not fully because they are expected to follow a structured form. Hollund bases her LSW approach on Thormann and Poulsen Infants Therapy, John Bowly Attachment Theory, Daniel

Stern Development Theory, Marte Meo and Lilli Nielsen methods and Gentle Teaching Philosophy. The end-product is a life story book with stories, pictures, drawings and documentary material. Hollund also arranges pre-training of the facilitators in LSW (Hollund 2007a; Hollund 2007b).

Dorothy Atkinson's (UK) research and LSW projects have a subjective value. In her study 'The Past Time Project', she worked with a group of people with ID that had good language skills; they could recall and reflect on the past. The objective was to capture the richness of the individual accounts within an insightful and reflective mode of a group setting. Participants were recruited via staff of the residential and day settings where they were current users. The project extended over a two-year period. Each meeting lasted for about one hour. Researchers facilitated the process, sometimes with help from staff members who translated and interpreted peoples' expressions (this was recorded). Memorabilia they used were questions: 'do you remember…', professionally produced reminiscence slides and tapes, authentic things, photographs etc. and when they read things they had told before, they remembered more. The end-product was the book *Past times* (Atkinson 1993).

Training tools or structured forms to use in life reviews have been developed over time. Examples are the *Life Story Pack* that Hussain and Raczka (1997) developed and Haight et.al. (1988, 2007) that uses a structured questionnaire to carry out life reviews with people with dementia in nursing homes and programmes from the Life Story Network (LSN), UK (Life Story Network 2013).

As mention before (2.7.2), there is a Norwegian book named *Min historie* (My history), which is the first and only one of its kind used

in services with people with ID. The book makes it possible to systematically insert information, texts and images about an individual (person). Today the book is sold out from the publisher and so is impossible to obtain (Olsen et al. 1994).

2.8.2 Competence among the interlocutors

For older adults with ID, their staff have a special value. There is an unreserved trust which means a serious responsibility for their providers. They consider the staff as their friends and only trustworthy persons, especially when they are sick and lack strength to take care of themselves (Folkestad 2003b; Jacobsen 2007; Thorsen 2005; Thorsen and Hegna Myrvang 2008; Westergård 2007). This situation raises some important issues about how well staff know their service users and also the importance of the stability and quality of the human resources which the services have.

Interlocutors in LSW often have limited training prior to exploring the service recipient's life story and sometimes they appear to use the information they obtain for different purposes (Foster and Banes 2009; Haber 2006; Svendsen 2004). Haber is one of those who questioned the huge amount of staff, students and family members, with limited prior training doing life review with vulnerable populations. He was concerned that these practitioners might harm the mental health of older adults instead of improving it.

> *"Researchers, in fact, have warned against allowing well-meaning but inadequately trained practitioners to break down the use of purposeful denial or non-reflection as a primary defence mechanism …. Denial, in fact, may be adaptive in early bereavement and some health setbacks, and the encouragement of individuals to review their past or current situation may distress them."* (Haber 2006: 164).

A long term goal, suggests Haber, may be the development of certificated training that enhances the likelihood of safe and effective interventions (Haber 2006).

Also Ken Holth argues that people who help a person to do LSW, should be trained because of the emotional side. He suggests that they should know what to start with and when to stop and how to deal with the stories they hear. He says it depends on the sensitivity that a person has and not whether he or she is trained in psychology or not (Kaiser 2008).

Despite this Haight et.al., who reviewed nearly 100 life reviews, reported that only seven percent of these were associated with negative outcomes (Haight 1995). About 15 years after this Wood conducted a literature review about reminiscence therapy for people with dementia and did not find any reported harmful effects of the outcomes (Woods et al. 2009). Therefore, in this study the storytellers' choice of an interlocutor and a written LSW programme in accessible text was more important than the education or the training the interlocutor may have.

2.8.3 An emphasis on positive experiences and feelings

In LSW based on positive psychology there is an emphasis on sharing positive experiences and feelings, rather than dwelling on traumas, which usually requires therapy (Brudal 2006; Meininger 2005; Seligman 2002; Van Puyenbroeck and Maes 2006).

Positive psychology represents a new perspective to the deviant perspective. It rejects the disease model (2.1) of human functioning, which has been central in psychological therapy after World War II.

Seligman declares that the pathological approach in psychology has neglected opportunities to build personal strength, which is the best way to change peoples' lives (Seligman 2002).

Research in positive psychology concludes that positive self-perceptions of ageing influence the length of life: persons with positive attitudes to being old, live up to seven and a half year longer than people with negative attitudes. This means that positive attitudes have more effect on people's ability to survive than other variables, for example gender, social economic status, functional health and lonesomeness, which are variables known from lifespan research (Levy et al. 2002).

An acceptance of the theories from positive psychology indicates that emphasises in personal experiences and perceptions will be important in the future and that research may be used to understand how to maintain and build positive identity among people with ID.

2.8.4 Relationship and communication

Communication is commonly described as *"a process in which something is shared or made public"* (Svare 2006: 19). It is more than an exchange of information and may be seen as a creative process which is fundamental to who we become and who we are (Lorentzen 2006; Svendsen 2012).

> *"Reality as we understand and perceive it is created in and through our communication. Thus, we also create ourselves - our identity- in and through communication with others."* (Lorentzen 2006: 132).

It is impossible to tell in one story everything that has happened from birth up to the time the story is told (2.6&3.1).

The story a person tells is always a summary, or highlights of life experiences and they are a repetition and a reproduction of the event. Stories are moveable/ dynamic and will be changed and revised during the time they are retold. A person's stories are always more than we can hear or see. A body reacts and interacts with experiences and sometimes we forget why we react to things or find it difficult to express our experiences in words. Some of these reactions can be past experiences that are too painful to remember and to tell other people (Horsdal 1999; Iversholt et al. 2003).

Storytellers may become more conscious about their own situation or things they talk about when they hear and see what they themselves are telling (Brudal 2006).

> *".... the focus person has to be at the centre of it, and they have to be listened to….that's one absolute rule, and everything else can be changed to fit in with that"* (The service user's Clark and Garland in Cambridge and Carnaby 2005: 80).

People select in terms of how they present themselves and what they remember from their life. From the position we have when the story is told, we are influenced by the context we are in. Also the way a person perceives himself when life stories are conveyed, influences what he chooses to tell (Thorsen and Hegna Myrvang 2008).

We are all basically social humans and knowledge of each other's lives brings us together, makes us bond with each other, to our history and our society (Iversholt et al. 2003). Good communication is essential so as to immerse oneself in the other's 'world' and to create shared experiences and good relations (Hanssen and Røkenes 2006). This feeling of equality is a must for an interlocutor to be able to understand and to get inside the mind and inner world of the storyteller. It builds on a sense of worth of self and others, a human value as a basis for the dialogue.

In LSW, mutual respect is a central part of communication and relationship. Interlocutors' should presuppose that the service users are experts on their own lives and that they themselves have the answers when it comes to what they need (Bredland, Linge and Vik 2011). Based on this human view, an empathic and respectful process may be created. It may also come naturally through experience.

In LSW, a key term in empathic conversation is 'emotional intelligence' and an interlocutor's reflection. In positive psychology as well as in PCA and LSW, the empathy and the listener's skills are emphasised. The storyteller is the protagonist of the conversation and their stories are most important. An interlocutor's main task is to invite the storyteller to come forward with their stories. It is important that they concentrate on the story that is being told and the storyteller's personality (2.6.1). They have to give them time and attention. Such confirmation is essential in empathic communication. One must be able to take on other people's reality without losing one's own, actively participate and not judge but accept people as they are, tolerate their feelings and reflect on their own work (Hamilton and Atkinson 2009).

A practical approach in this case is the 'empathic dialogue/ conversation' (Brudal 2006; Meininger 2005; Pörtner 2000; Van Puyenbroeck and Maes 2005). A great conversation is largely a dialogue that is characterized by reciprocity, goodwill, openness and collaboration, where the participants create something together and are listeners because they are interested in what is being said. They have a common project to create a new understanding, new insights or something else. This process requires openness for something new to arise. The outcome is not a foregone conclusion and it is obvious that something unexpected might happen. The dialogue lives when the

participants accept such uncertainty, instead of seeking security in their own beliefs and perceptions (Svare 2006). They need to let go of any personal 'agenda' and *"… listen without 'an inner noise' getting in the way"* (Newman 2010: 3). This does not mean not having any purpose or intention, it means to *"be fully present, open to the life and ideas of the person we are meeting, and to be more wholly ourselves"* (ibid: 3).

To be more open in a conversation with people who need our support, we have to open up for our own deeper thoughts*…" having no agenda may turn out to be our most powerful source of wisdom"* (Newman 2010: 4).

Empathy can be evaluated from a person's norms, perceptions and reviews and it is a central term in self-psychology and developmental psychology. *Empathic conversation* is a method in positive psychology that emphasizes peoples' self-esteem and gives attention to a person's development of positive emotions (Brudal 2006). It is very similar to principles in PCA which focus on (Pörtner 2000):

- Unconditional positive regard
- To accept the other person without judgment
- Be consciously aware of one's own expectations and feelings
- To discriminate this from what is perceived in the other person (congruence)

Brudal claims that when people have empathy and can master empathic conversation, they prevent the risk of themselves or others getting a psychic imbalance (Brudal 2006). According to the PCA and positive psychology, three elements strengthen and build personal growth (Brudal 2006; Pörtner 2000):

– Becoming conscious of one's own feelings

- Talking about feelings
- Communicating feelings and experiences to other persons or groups

When people describe themselves, their life situation and their way of managing their life, a story emerges that contains their perceptions and experiences about their lived life. The way they tell it, shows how they communicate and process their experiences. Often their stories are not coherent and the terms they use are not logical or well defined. Causal explanations are perhaps not precise and they may tell with passion their stories as if it is remembered 'just now' (Gùstafsson and Raminan 2003). According to McAdams, we often select and interpret our life experiences rather than simply distort the truth (2.5.2.1-2). We instead choose the events that we consider tell others who we are and provide our lives with some semblance of unity and purpose (McAdams 2001).

> *"Oral sources… are not always reliable in point of fact. Rather than being a weakness, this is however, their strength: error, inventions and myths lead us through and beyond facts to their meanings."* (Portelli 1991: 2)

It needs to be made clear that the goal of LSW in this study is not to come up with a story that is true to the events portrayed, but to come up with a story that is personally true. To ask if a story is 'true' is too often limited to the question of whether or not the events depicted in the story correspond to what has taken place and whether the story accurately reflects those events. 'Truth' has a wider range of meaning than this. For example, we can be true to some principle, or we can be true to or faithful to our basic underlying nature, to a promise or a rule (Heap 2002).

One challenge for the interlocutor may be to ‘rebuild themselves’ from a person who normally ‘knows best’ to one who is able to show an attitude and practice of trust to the storyteller’s own resources, to respect their reality and knowledge about their own inner life. When storytellers get a feeling of equality, they may feel more free to express their own feelings, thoughts and experiences (Brudal 2006).

In a *dialogic communication process*, it is important to ensure that even if people contribute differently, they will contribute in an equitable manner. Something is created through sharing what each can contribute, based on own assumptions (Svare 2006). The interlocutor needs to be aware of the inequality and be dynamic, so that both parts can complement each other. Questions of empowerment (2.2) always will occur in the relationships between service user and the system and between the service user and their service providers (Braye and Preston-Shoot 1995).

2.8.5 Prospective end-products of life story work

It is most important that the end-product in a LSW process is personalised and that the product is valuable to those who have told their life stories (Hussain and Raczka 1997). A way of achieving this is that the storyteller decides the process and the product (table 2.1) they want to make out of the process of LSW (5).

Figure 2.1: Prospective end-products in life story work

2.9 Summary

Parts of the history, today's policy and discussions/models that inform the understanding of ID and disability in general, constitute an important basis for how this study was designed and the results it was possible to produce. Discourses that have informed policy and practice in the disability field vary from country to country, even if they have influenced each other. Movements, models, theories, ideas and discourses that are outlined in the introduction and in the beginning of chapter two, indicate a number of discussions in this field that may have an impact on the shape of future research and an overall understanding of the environment in which this study takes place.

The importance of knowing the person who receives services seems to be a natural consequence of the political decisions and influences of professionals who highlight the importance of PCA. In spite of all this, there is little focus in Norway on research into person-centred practice and the importance of identity and life stories in this approach. It was expected that personality theories would be present more often in studies of PCA and LSW than the literature reviews shows was the case.

There is a lack of theories and studies of older adults with ID, their identities and life stories. History shows that these older adults have not received much attention in their personal development. People's life stories are a source for personal growth and identity development. Generativity theory and the redemptive self are perspectives that are explored and so are approaches that may help older adults to use their resources and life experiences to grow their personality and identity. The tension between life stories and identity (roots, relations, social role etc.) are not much explored for people with ID. The connections McAdams makes in his model mean that the application of a model to promote LSW as a service in Norway may be analysed in a wider spectrum of the person centred approach.

The literature reviewed in this thesis indicates that there is a need for documentation of people's ability to carry out a liberating examination of themselves and their own self-image. There is also a need to obtain knowledge on the benefits LSW might bring. LSW is not prevalent in Norway. It also does not have the long history as in Denmark or the UK. The way the ability to tell personal life stories develops in a life span may help us to understand that people with ID may need help with their LSW. A life story telling cannot be manifested without the underlying cognitive process of remembering and counting the

produced stories. This is a fact that makes it troublesome for some people with a severe degree of cognitive loss to tell their stories without the help of others. The interlocutors' role and an emphasis on empowerment, positive experiences, good relationships and communication are the most central aspects of a LSW programme. So is creativity in producing an end-product.

The literature review in this section forms a link to the next section, which constitutes an important basis for the methodology and design used in this study.

3 Methodologies, design, data collection and analytical approach

The principal aim of this research is to develop and applicate a model to promote LSW as a service in Norway (1.5). The study therefore, based on this aim, takes a social, psychological and a pedagogical perspective. The purpose and the objectives of the study, the researcher's position and the characteristics of the participants (and audience) are all factors that define this study (Robson 2002). This study validates the collected data through consistency between the philosophical basis and the methods adopted (Morse, Kuzel and Swanson 2001).

This chapter begins with a brief review of the ontology and epistemology on which this study is based. Chapter 3.1 provides a first review of interpretative phenomenological analysis (IPA) and a discussion of nuances which are relevant to this study (3.1.1). This is followed by an examination of concepts in critical realism that are relevant to this study (3.1.2). Combining these two methodological stances seems to be a rarely reported approach. No attempt is, however, made to perform deep analysis of realist philosophy and phenomenology in general and of critical realist and IPA philosophy in particular. Only the most central issues are reviewed. Concerns that are important to bear in mind when people with intellectual disabilities are included in a study are also covered.

The following sections review the flexible (qualitative) research design consistent for this study. These are the Delphi approach (3.2.1) and participatory action research (PAR) (3.2.2) in phase one and 'pre-interview, intervention and post-interview (PIP)' in phase two (3.2.3).

The section on ethical considerations (3.3) provides information on national approval bodies (3.3.1), informed consent and other vulnerable participant considerations (3.3.2). It is followed by section 3.4 on the sampling process and the inclusion and exclusion criteria in both phases for the three different groups of participants. Triangulation of data collection (3.5) describes pre-questionnaires, interviews (3.5.1), piloting (3.5.1.1) and self-observations and reports (3.5.2).

The section on how phase one, the preparatory phase, was carried out (3.6) includes:

- An outline of a step-by-step-plan developed to secure ethical and practical concerns before data was collected from the 'LSW experts'
- A description of the topics in the pre-questionnaires and the interviews with 'LSW experts'
- Preparation of the methods used to carry out phase two (3.6.1), one part of the participatory action research

Accomplishment of phase two, the PIP (3.7), begins with a map of the design (fig.3.1) that shows data collection and intervention strategies which;

- Define and describe the distinct roles: the obligations assigned to the participant and the researcher (3.7.1)
- Describe data collection (3.7.2):
    - Step-by-step-plan

- Description of the topics in the pre-questionnaires and the interviews with storytellers and their interlocutors
- Weekly reports
- Closing parties

Accomplishment of the analysis (3.8) provides evidence on the impact of life story work on participants. It also provides evidence on the contribution of life story work to the delivery of a person centred approach to older adults with intellectual disabilities in Norway. Table 3.1 in chapter 3.8 gives an overview of all the data that was analysed in both phases (3.8.1 & 3.8.2) to describe LSW elements. The step-by-step analysis was supported by a structured analysis model and NVivo. The summary is at the end of this chapter (3.9).

This research has been conducted in three different countries, the majority in Norwegian. The researcher's experiences with translation processes in both phases are described. The paper gives an overview of the steps that were taken and hours used in each step of the process. An account has also been written of the reflections and experiences of the researcher in interviews, especially in interviews with the storytellers. These accounts are not included in this thesis. They contain too much material and their inclusion would mean the maximum number of words permitted for this thesis would be exceeded. They will therefore be subjects of subsequent publications.

3.1 Epistemology and ontology

A number of philosophical and theoretical perspectives may be used to underpin a study of LSW. The narrative method is one approach. This approach is used in LSW research to explore peoples' life stories.

These stories, which reveal knowledge about the person and the world, can be interpreted to provide an understanding of the life and culture that created the story (Patton 2002). This study is, however, primarily about the development and application of a model for determining whether LSW has a value as a service for people with ID. The study is not an exploration of peoples' life stories and the narrative method has therefore been set aside.

The historical context (1) around today's older adults with ID has meant that it was natural to be critical about the way society has treated them and still treats them. The critical realism perspective lays a fruitful foundation for an interdisciplinary research field, for user studies in particular and studies with many levels of information (Wikgren 2005). It also fulfils the emancipatory potential of this study (Ritchie and Lewis 2003; Robson 2002). The open stance of critical realism also makes it easier to combine methodologies. Interpretative phenomenological analysis (IPA) was also included to counter the weak elements in critical realism. IPA can be easily related to phenomena in social psychology, such as identity and personal development, which is a focus in this study (Pawson and Tilley 2004; Smith, Flowers and Larkin 2009).

The empirical focus looks at events in relation to the process and impact of LSW. It is not transparent. An approach that provides more than a mere description is therefore necessary (Wikgren 2005). The reductionist approaches are rejected. The impact of LSW is therefore studied within the complexity of the real life. Anything else would not be appropriate (Gibson et al. 2004).

The following sections give a brief review of the range of philosophical perspectives that lead to an explanation of and a justification for the selection of design, research strategies and analysis outlined in chapters 3.2-3.8.

3.1.1 Interpretative phenomenological analysis (IPA)

Phenomenology is (apart from social construction/constructivism) the most widely used philosophical perspective in qualitative inquiries. The philosophical tradition of phenomenology was launched in the first half of the 20th century by Edmund Husserl, Martin Heidegger, Maurice Merleau-Ponty, Jean-Paul Sartre et al. In 1913 Edmund H. Husserl (1859-1938) defined phenomenology as the study of how people describe things, the assumption being that we may only know what we experience. This means that people can only communicate what they know from their own subjective experiences (Patton 2002; Robson 2002; Smith 2011; Sonnemann 1954; Spiegelberg 1972). According to contemporary psychologists such as Atkinson, Atkinson and Hilgard, a focus on *"the individual's unique perception and interpretation of events, the phenomenological approach brings back the role of private experience to the study of personality."* Phenomenology, more than any other theory, *"concentrates on the whole, healthy person and emphasizes a positive, optimistic view on human nature."* (Atkinson, Atkinson and Hilgard 1983: 402).

Interpretative phenomenological analysis (IPA) was first introduced by Jonathan Smith in 1996 as a contribution to health psychology (Smith 1996). IPA builds on concepts and ideas that have a long history in philosophy of knowledge. It draws widely and selectively from a range of ideas from phenomenology, hermeneutics and

idiography. IPA is concerned with the examination of how a phenomenon appears. It is dynamic in nature and can be used in a wide range of applications. It fits well into a study that includes participants with different positions who tell about their experiences in LSW.

3.1.1.1 Experiences

IPA follows the approach encouraged by Edmund Gustav Albrecht Husserl (1859-1938), that experiences should be examined in the way they occur and in their own terms (Smith 1996). Husserl describes the focus on experiences and the description of the particular and essential features of experiences as the 'content of conscious experience'. This perspective implies that science is a *"second-order knowledge system, which depends ultimately upon first order personal experience"* (Smith, Flowers and Larkin 2009: 15, 16). Personal experience is the individual psychological process of perception, awareness and consciousness (ibid).

Some of the informants in this study may have trouble reflecting upon and accurately telling about their experiences. Their communication difficulties mean that the form and content of written and spoken words are particularly important. Those with ID often need to be asked simple questions and be given key words that can help them to identify the essential qualities of their experiences. This, however, does mean that the risk of researchers asking leading questions is high. Despite this risk, the clear line of approach used has been to ask every participant about their experiences and to find essential features of their experiences that can illuminate experiences of others (Gjærum 2010; Smith, Flowers and Larkin 2009).

The researcher's prior experience with people with ID and their staff is a clear advantage. It made it easier to speak 'the language' they are familiar with. However, one can question to what extent the 'adapted communication' captures understanding and experiences of participants. How much of their 'reality' does the study capture? (Denzin 1991).

The avoidance of taking things or people for granted is a further issue from Husserl that IPA has adopted. People with ID may have experienced that parents and staff speak for them, tell them what to do without asking them first or tell others about who they are and what they are able to do even if they are able to speak for themselves (Heia and Westergård 2014).

If the voices of those with ID are to be heard, then it is crucial that the experience storytellers speak about and that spoken by interlocutors and 'LSW experts' are distinguished between. The Bos, Van de Goor and Schols study shows the importance of this when developing an instrument to measure the quality of care and services. They focussed on the client's perspective and found a difference between what parents told them and what their children with ID told them about service quality (Bos, Van de Goor and Schols 2006). Older adults with ID are in general able to tell about their life, their needs and wishes. They can tell about their experiences and many of them remember historical events remarkably well (Thorsen 2005). There can therefore be no justifiable reason for keeping the views and experiences of older adults with ID out of a study which is about them and 'their' public services. They can provide a vital and unique perspective.

Experienced interlocutors were also challenged. They were asked to stop and think about their own practice, knowledge and attitudes and their relationship to the storyteller, who the storyteller is, what the storyteller's life experiences are and their wishes for the future. This process of reflecting upon experiences is described by Husserl as 'intentionality' and is defined as the relationship between processes, consciousness and the phenomenon of attention (Smith, Flowers and Larkin 2009).

3.1.1.2 Meaning making

Attempting to 'bracket' and 'reduce' are other influences taken from Husserl. 'Bracketing' and 'reducing' should be taken into consideration to ensure the essence of the experiences is obtained from the process of generalisation of examining, describing and reflecting upon every 'salient particularity' (Smith 1996). The intention is that researchers are lead away from the distraction of their own preconceptions. Interpretations may, however, be wrong if the researcher does not understand the situation of an interviewee with a communication handicap and the meaning of self-determination.

A further (Heidegger) concern is that practical activities and relationships are made meaningful in LSW; 'what is possible' and 'what is meaningful' (worldliness). Does LSW have a significance for individuals and a value in services for older adults with ID? What about 'intersubjectivity', the shared overlapping and relational nature of engagement? Intersubjectivity may be related to the way storyteller and interlocutor interact, their ability to communicate and how they make sense of each other.

Engagement in LSW involves self-reflection and affective concerns defined by time and place. This supports the main view in IPA that people's being in the world is always temporal, perspectival, relational and that the interpretation of meaning making is relevant in a psychological context (Smith, Flowers and Larkin 2009).

IPA aims to examine peoples' lived experiences without using predefined category systems (Smith, Flowers and Larkin 2009: 32). Subjective experiences in this study are described as particular moments of significance in the participants' life-situation and are incorporated into LSW. Participant reflection upon and the making sense of the embodied, cognitive, affective and existential impacts of the LSW programme was an important part of data collection.

Peoples' life stories are unique (2.6.3). One question that therefore arises is how different do LSW participants see themselves in relation to everything else in the world. Maurice Merlau-Pointy (1908-1961) suggests that people see themselves as being different "because our sense of self is holistic and is engaged in looking at the world" (Smith, Flowers and Larkin 2009: 18). We perceive others as just an element of behaviour and in a world in which we cannot see everything at once. We can experience empathy for another person. We cannot, however, feel the same or experience the same as they do because our feelings are in our body. This perspective of the body can shape the fundamental character of what people tell about the world. It is important to understand this and take this into consideration in LSW where emotions and difficult stories may be told (ibid).

3.1.1.3 The developmental and processual aspects of human being

The existential part of the phenomenology that influences IPA comes mainly from the philosopher Jean-Paul Sartre (1905-1980). The 'developmental, processual aspects of human being' relates in this study to the way storytellers and interlocutors experience LSW. LSW is action-oriented. Participants pass through a process which they define themselves and ends with a result such as an album with photos and stories. They seek, in LSW, the meaning of lived experiences, which unfurls through the course of the storyteller's life project. Storytellers who become conscious of things that are absent in their lives today (interests, values, memories feelings of pride about people they have meet or things they have done) can find this and helps them to define themselves, the 'world' they are a part of, their relationships and who they want to be. LSW may help storytellers to see the 'world' as more than themselves and to think about how the presence of others shapes their own perception. One example being others involved in the participant's LSW such as an interlocutor who supports a storyteller (Smith, Flowers and Larkin 2009).

The direction of perception is described by Sartre as 'looking through a keyhole'. This can also occur in what happens between storytellers and interlocutors in LSW. The interlocutor may be identified as the one who is 'looking through the keyhole'. The interlocutor does this to influence the storyteller's self-conciseness, to make the storyteller's emotions more apparent and easier to make sense of (Smith, Flowers and Larkin 2009). This 'interpersonal context' is an important part of the LSW programme and of the stimulation of the personal development of storytellers and interlocutors.

Another issue Sartre has described is the complexity of freedom and the responsibility of every human to deal with their life (ibid). People with ID may experience a higher degree of this complexity than those without disability. Data collection has therefore been triangulated to find out as much as possible about this complexity (3.5).

3.1.1.4 Interpretation

The theory of interpretation, which is influenced by hermeneutics, informs the methods and purposes of interpretation. It emphasises human beings as sense-making creatures, research being mostly subjectivist (Söder 2009). A subjectivist approach opens this study to exploring experiences that are meaningful and particularly significant (3.1.1.2).

Seeking interpretations of 'hidden meaning' is as relevant to interviews as it is to analysis. Participants with communication difficulties were asked about the things they spoke about in different ways and to try and find out what they 'really' wanted to say. It is sometimes necessary to interpret what they say and ask them if this interpretation is correct. This approach seems to be related to the primary IPA aim of *"… to examine 'the thing itself' as it appears to show itself to us"* (Smith, Flowers and Larkin 2009: 24).

Not allowing fore-conception to be present is a clear and continuous aspect of interpretation. The 'hermeneutic circle' is a model that can be used to work in a reflective, dynamic and structured way with preconceptions (Smith, Flowers and Larkin 2009). The researcher's interest in and long-time experience in the field, even so, always risks the researcher bringing too many of their own thoughts, aspirations,

feelings and orientations into the study. Personal feelings and preconceptions do, however, not tell us anything about how 'objective' the researcher is. Getting around that which a person is simply not aware of is not possible (Ahern 1999; Kirby and McKenna 1989). Presupposition based on experiences can, however, also be used in a beneficial way.

In this study, the researcher's 'understanding' is primarily based on the content of what participants tell about their experiences. It is also and secondarily based on participants' meaning. 'Understanding' based on participant meaning is derived in relation to the context of this study and is influenced by the moment of interpretation (According to Gadamer in Smith, Flowers and Larkin 2009: 27). A recommendation when carrying out IPA is to take a 'dual role' and to engage more in the participants than in the process of 'bracketing' prior concerns. The question arose of whether participating in LSW observation could give valuable data or not. Observation would have given the researcher more knowledge about the LSW process before the post-interview took place. However, the assumptions for interviews before and after LSW are different, which could undermine the reliability and the aims of this study.

Assessment of the interpretative work is influenced by participant's 'real' experiences of LSW. Relevant LSW theory and related theme theories were also utilized to shed light on this. Interpretation by 'reading within the terms' was mainly carried out by looking at several sources of information provided to the researcher by the person such as photographs, weekly reports and pre- and post-interviews. Similarities and differences between the person and other participants were also looked at. *"In a good IPA study, it should be possible to parse the account of both for shared themes, and for the*

distinctive voices and variations on those themes" (Smith, Flowers and Larkin 2009: 38). Interlocutors sometimes said things that are based on their perspective, which the researcher could use to illuminate things the storytellers had told about and vice versa.

3.1.1.5 The particular

The ideographic influence of IPA is concerned with the particular. Smith et.al. claim that *"IPA is committed to the detailed examination of the particular case. It wants to know in detail what the experience for this person is like, what sense this particular person is making of what is happening to them."* (Smith, Flowers and Larkin 2009: 3).

The two levels that commitment to the particular operates at are;

1) Commitment to detail (depth, thorough and systematic analysis)
2) Commitment to the understanding of how particular experiential phenomena (the LSW process, relationships between storytellers and their interlocutors) have been understood e.g. by the participants in this study

This therefore requires a small, purposefully-selected and carefully-situated sampling process. IPA also opens up for moving to more general claims after the potential of the case has been realized (see 3.5).

3.1.1.6 General claims

Greater focus is placed in this study on general claims than narratives from single cases. Phenomena located 'in the particular' are established as generalisations (Harré 1979), at the same time as the data allows particular claims to be retrieved for any of the participants. Data is primarily visualised in unique perspectives or elaborations of various phenomena (Smith, Flowers and Larkin 2009).

The descriptive part of the analysis consists of a number of tables. This approach is not used to explore individual differences, but to show similarities and divergences (ibid). Convergence and divergence are related to three groups of informants (the experts, the storytellers and the interlocutors). They are described in three separate sections in this thesis (4, 5 & 6). Some results are compared and presented in tables to make the data more understandable and also to help the reader to assess the evidence in relation to the different perspectives of participants.

One challenge faced when using IPA is the translation of phenomenological philosophy into a practical and *''coherent approach to the collection and analysis of third –person data"* (Smith, Flowers and Larkin 2009: 33). A further challenge lies in validating the concepts used. This is, however, one of the strengths of critical realism. Combining the two approaches therefore opens up the possibility for elements of numbering in the analysis (Patton 2002; van Manen 1990).

3.1.2 Critical realism

> *"What will produce the greatest overall change?" to "What works best, for whom, and under what circumstances?"* (Robson 2002: 39).

Critical realism is a variation of realism. There is a long critical realism tradition in the philosophy of science and in social science. It provides a basis for the selection of practically orientated theories. The focus is on the tangible and the examination of the nature of knowledge itself. Knowledge is recognised as being a social and historical product, related to and defined by a particular point in time, situation or culture (Patton 2002; Robson 2002).

This position underpins research studies in a number of fields including practice and value-based professions (e.g. Anastas 1998), the learning disabilities field (e.g. Warner 1993), psychology (e.g. Shames 1990) and social work (e.g. Kazi 2000). Critical realist approaches are increasingly used to study identity, reflexivity or agency in mainstream journals (O'Mahoney 2011).

Critical realism began with the British philosopher Baskhar's writings, *A Realist Theory of Science* (1978) and *The Possibility of Naturalism* (1979) (Bhaskar 1986; Wikgren 2005). It has been developed over the past four decades and provides a third way between positivism (the search for universal laws of causation) and relativism/ interpretivism (rejection of laws of causation in human endeavours): *"Critical realism is not only the ontologically least restrictive perspective, but also the epistemologically most heuristically suggestive"* (Bhaskar and Danermark 2006: 295).

The critical realist philosophical approach recognises the reality of the natural world and of events and discourses in the social world. As described in section two, these perspectives are highly relevant to the

situation of people with ID. Those with ID acquire experiences in their interactions with society (the social and natural environment) based on their physical/intellectual impairment (biological nature).

In LSW, our concepts and beliefs are historically generated and conditioned. An individual psychological phenomenon is, however, primarily formed in a cultural-historical process (McAdams 1996). Critical realism implies a defence of the possibility of causal explanation. It however also implies an acknowledgement of the hermeneutic notion that knowledge is communicatively constructed. This means that the researcher has to identify the structures that generate events and discourses if the researcher is to understand how they can change participants' lives (Bhaskar 1989; Wikgren 2005). Much of this perspective is also found in McAdam's theories (2.6). His focus is, however, more on the knowledge and overview gained by those working with their life stories.

A wide range of competing approaches\models of disability can be included into discussions about the contribution of critical realism's comparative frameworks and the role theory has in disability research. Critical realism provides a fruitful perspective in any interdisciplinary approach to disability research, these fields often being characterised by complex relations or gaps in theories and models. Critical realism is therefore a philosophy and a social theory that spans various knowledge bases, professional practitioners and researchers (Bhaskar and Danermark 2006; Parker 2010; Wikgren 2005). No matter which method is used, the role of critical realism theory is to explain the hidden powers, the processes or mechanisms that produce effects or events, events maybe being seen and observed. Social mechanisms are not readily observable. Theory and abstraction are therefore important

(Wikgren 2005). The literature reviews in this study are therefore and because of this, essential (Fox 2013).

3.1.2.1 Critical realism - concepts of a stratified social reality and human agency

Critical realists are emphatic about the fallacy of blending the social and the individual level into each other (Wikgren 2005). It is, for example, important to distinguish between human action and socio-cultural structure when studying the impacts of LSW.

A key requirement in this stance is that heed is paid to the different layers of *social reality* which make up and surround a LSW programme as defined by the following levels (Pawson and Tilley 2004):

i) The individual capacities of the storyteller and the interlocutor
ii) The interpersonal relationship created between them
iii) The institutional balance (local services as day centre and residential) and desirable impacts of these
iv) The wider infrastructural psychosocial system and local service that support or undermine the establishment and duration of LSW, including the additional possible impact of personal development, empowerment and human rights on participants

The causes of what occurs at one level are not automatically reproduced at a lower or higher level. The reason for this is that something qualitatively new emerges at each level (Harvey 2002).

For two dimensions, the distinction between levels does not lie in the entities but in the generative mechanisms that operate at each level (Harvey 2002; Wikgren 2005):

> The *first dimension* is the distinction between events that we can experience and describe and the hidden, but nonetheless real, mechanisms behind them. An example of this is a storyteller that only wants to tell stories from one part of their life and not from the time they spent in an institution.
>
> The *second dimension* is that reality is assumed to consist of hierarchically ordered levels, lower levels creating the conditions for but not determining higher level. An example of this may be impairments (biologically, individual level) that hinder a person from expressing what they think and want (individually social level). This dimension is an important concern in this study, but not essential in LSW.

This may be related to the so-called 'Thomas's Theorem': "What is defined or perceived by people as real is real in its consequences" (Thomas and Thomas, 1928: 572, in Patton 2002: 96). It has been questioned whether the people with ID or psychiatric diseases that have been studied in research have the ability to define their reality. They have historically not been considered to have such a capability - to be able to communicate this (1.2). Today most people with ID are, however, considered to be able to communicate contextually embedded and interpersonally forged knowledge of what they perceive as reality (Neimeyer 1993).

The postmodern influence is also considered. This influence pertains it is not possible to capture the whole of reality or to or to find a 'single window' through which the whole of reality can be viewed (Patton

2002). This posture, called the '*crises of representation*' (ibid), is considered for participants in this study. They reside in a part of our society that the majority never experience. Housing and daycentres for people with ID are a specialised and not a mainstream service. This means that the perceptions of 'true reality' by these persons may have a limited generalised relevance to other parts of society. Despite this limitation, it is important that local authority decision-makers know 'the truth' as experienced by those in this marginalised group. Knowledge of how this marginalised group experiences their situation can help decision makers manage the challenges better and allow them to be better equipped to decide the 'right policy' for services.

Another central concept is 'human agency' (the capacity of human beings to make choices). This nuanced view distinguishes between (Archer 1995; Archer 2000):

i) Persons as individual human beings, emergent from (but not reducible to) their biological make-up
ii) Agents as collective categories, e.g. service users/providers
iii) Social actors emerging from collective agents, enabled and constrained by their social role and the sociocultural situations in which they act, e.g. the storyteller and interlocutor in LSW

The use of and the understanding of 'human agency' may be helpful in an analysis of the impacts LSW has on, for example, interlocutors. There is also a conceptual distinction between:

a) Structure and agency
b) The position-practice system
c) Positions where individuals act

Interlocutors have, for example, a point of contact with structures through the roles they occupy or assume to be in. These are related to their employment in the service and also through their situation or the context they are working in. Structures such as the rosters which control how/when staff work, have their own independent mechanisms and provide the grounds for different LSW practice such as meetings between the storyteller and their interlocutors (Archer 1995).

Another approach that provides an analytical framework in which the interrelationships between agency, structure and culture may be examined, is the 'Morphogenetic approach' (Archer 1995; 1996; 2000). In this approach, the focus is on change. Each system has its own relative autonomy and emergent powers and these form constraints and opportunities for other systems. Society and culture are the products of human activity and are constantly elaborated or reinforced by human activity. Social and cultural structures are also pre-existent, which gives them their autonomy as possible objects of investigation (Archer 1995; 1996; 2000; Harvey 2002; Wikgren 2005).

Criticism of critical realism comes from, among others, Klein (2004) and Mutch (1999, 2002). These scientists express the need for a greater awareness of structure and process and for the human being acting as a person, a collective agent, and as a social actor (Wikgren 2005). In this study, many of the structures and processes are defined in the LSW programme. The person's role as a *social actor* is also clearly defined in descriptions of participant role expectations in LSW (3.7.1).

3.1.2.2 The importance of contextualisation

A person is always situated in numerous contexts which affect behaviour and interactions with other people or the way environments unfold. Context also creates a dynamic basis. Participant actions and interaction may therefore ultimately be influenced by a coincidence of competencies and facilities (Archer 1995; Bhaskar 1998). The focus therefore has to be, based on this perspective, on the full complexity of human rationalisation[8] as the situation emerges (Kaplan and Maxwell 1994).

A participant's experiences and the relevance of LSW cannot be assessed without paying attention to the cultural ideas, social rules and relations that impact the participant as a person, an agent, and a social actor. Wikgren (2005) warns that *"*social and cultural structures exist independent of our knowledge of them and have implications as to how we regard and study many central problems*"* (p.19). In LSW, a range of contextual factors may be applied to different situations and locations such as day centres, homes or at a party to celebrate LSW. Contextual factors can also include the researcher's expectations of the interlocutor's role and the storyteller's sense of their responsibility in their LSW.

Contextual influences may also constitute a form of 'power' including the interlocutor's competences, facilities for carrying out LSW, the opportunities the storyteller is given, the circumstances under which

[8] The process by which people give meaning to experience.

LSW is conducted and the beliefs (theories and values) of participants and people around. All may have an enormous, even controlling, impact on what is produced. They all constitute underlying generative mechanisms that are expressed differently in different contexts. The properties possessed by the social and cultural forms, such as the service, administrative systems, work tasks and everyday life situations, may be very different from those possessed by the interlocutor and which the interlocutor is able to activate, such as their personality, reasons, intentions and plans (Wikgren 2005).

Participants and the researcher both have their own personal backgrounds and experiences that influence their emotions or behaviour and which they bring with them into the study (Robson 2002). Some participants can experience feelings of stress during the LSW process because they are talking about difficult things. They may become ill or the timeframe for completing the LSW process may be too short because, for example, they go into considerable depth about an event or issue.

The service is also in continuous change. The nature and scope of this change depends on the resources available, leadership and local government plans. This can impact participants' opportunity to participate in and complete the LSW programme of this study. Moves or changes in one part of the service may also bring consequences for other parts of the service. For example, a day centre that decides to carry out LSW with many of their service users will have to draw in resources from other parts of the service. LSW is carried out in addition to normal day-to-day operations and can result in outcomes that influence individuals and the service as a whole, such as an entire day centre. It might also influence society and the theories and procedures of professionals.

3.1.2.3 Explanations

Describing a phenomenon and providing an explanation of its occurrence answers a ‘why-question’. Critical realists seek to improve the understanding of the causal mechanisms and corresponding causal contexts that are required to generate the outcome (Bhaskar and Danermark 2006; Fox 2013; Raduescu and Vessey 2009).

Critical realism is open to practical application through reference to all theory. Even so, there are a number of methods and tools that can be combined to reveal causal mechanisms and contexts. These methodological approaches should, however, be designed for open systems. Instances of causality should, therefore, only be seen as non-predictable and as only tendencies rather than indisputable consequences.

Mechanisms are recognisable causal patterns that occur frequently and that allow us to explain but not to predict (Elster 1998). This differs from the interpretivist position, in which theory describes the conditions or the context for the production of meaningful experiences (Wikgren 2005).

An understanding of the mechanisms at work and the context in which they operate provides a theoretical understanding of what is going on. This allows effects to be optimised by making appropriate changes to the context or by finding alternative ways to conduct this (Robson 2002). An explanation constructed in terms of the mechanisms of psychological or social phenomena shows how a specific event has occurred. The outcome of an action depends on the mechanisms acting in that particular context. This is a condition which allows a

reaction to take place. More than one mechanism may also be involved (Robson 2002). There will always be an interaction between context and mechanism in the LSW programme. It is this interaction that creates the LSW programme's impacts or outcomes: Context + Mechanism during the LSW programme period = Outcome/impact from the LSW programme (Pawson and Tilley 2008).

'Interpretation' is a central term in IPA. In critical realism, 'interpretation' is related specifically to discursive mechanisms; viewed as both transient and corrigible (Bhaskar and Danermark 2006). Mechanisms are the factors that have an impact on people and can be related to accessibility, information, needs and expectations (Robson 2002). Mechanisms in this study include:

> *Mechanisms of accessibility*: inclusion criteria and the gatekeeper's influence on the participants' interest in the study, pre-information in accessible text, time to conduct LSW, the feeling of trust in the researcher and their interlocutors.
>
> *Mechanisms of information*: about the project, quality of the information and the way it is given, disturbances within the environment when information was given.
>
> *Mechanism of needs and expectations*: the physical and verbal support, motivation, expectations before LSW began.

The above mechanisms may be defined as the resources made available to this study that enables the study to be carried out in a positive way. LSW mechanisms are the processes behind how participants interpret and act in response to the intervention strategy (the LSW programme).

This is why the first phase developed and presented the processes through which the program may work, which in turn was used as a prelude to carrying out the program and determining its impact.

The *interplay of mechanisms* (or forms of causality) was, however, a concern - the contexts and effects at distinct levels of the 'reality' contained in this study. Bhaskar & Danermark emphasise the importance of including biological, psychological, social and cultural factors in order to fully understand all mechanisms contributing to a situation. If all are not taken into account, then only a fragmentary understanding of a person's situation will be obtained, so reducing the opportunity to determine a good strategy for improving this person's situation. All phenomena of disability need, for example, to be understood in terms of a *laminated system*, such as bodily, psychic and social components. The relative importance and specific role of these components varies and is always an empirical question (Bhaskar and Danermark 2006).

The model of explanation used in this study allows for the incorporation of the participants' knowledge and values. This may, however, correspond with negative labelling. This is an important concern (Robson 2002). Critical realism involves an emancipatory dimension and the study should therefore do more than provide a 'description of LSW'. We also need to be critical of the explanations offered and ask whether the participants have an adequate understanding of their situation or their role. If not, then we need to explain why not (Manicas 1998).

3.1.2.5 Limitations related to the study of identity and the Self

Critical realism has been developed, at the macro level, in many fields. However at the micro level, *"where terms such as the individual, person or Self might be found, pickings are far slimmer"* (O'Mahoney 2011: 123). Margaret Archer (1943-) claims that critical realism's contribution is confined to very narrow aspects of the Self, particularly agency or reflexivity (Archer 2000). O'Mahoney claims that this relative paucity of research on the Self has primed the area for further development of critical realist applications and that *"the potential for establishing critical realism at the micro level is promising and has begun in earnest"* (O'Mahoney 2011: 125).

A stratified view of human agency may be useful in LSW when studying impacts. It can allow the researcher to isolate the constraints of individual psychology/differences from the reactions of staff and storytellers. The Self, which is a central concept in personality psychology and is related to the concept identity, is more difficult to define in a stratified view of human agency. According to O'Mahoney *"there is considerable work to be done in establishing a tradition of critical realist analyses of the Self, not simply in empirical analyses but also in methodological accounts"* (O'Mahoney 2011: 127).

3.1.2.6 The emancipatory potential in critical realism

> *"The main task of critical research is seen as being one of social critique, whereby the restrictive and alienating conditions of the status quo are brought to light."* (Myers 1997).

According to Everitt and Hardiker, feminism and emancipatory approaches are a part of the 'critical approaches' (Everitt and Hardiker 1996). The emancipatory potential for social research functions in critical realism is an impetus for change. However, we must remember

that ‘false’ understandings and actions may be identified (Bhaskar 1986).

The emancipatory potential is shown in a growing interest in evidence-based policy and health and social care (Hanley 2005). There are some good examples of participatory research in LSW, both in the US and later in the UK (Atkinson 2004; Atkinson, Jackson and Walmsley 1997). There are few examples from Norway, on people with psychiatric diseases (Hummelvoll 2008).

Emancipatory research focuses on the lives and experiences of groups that historically have been marginalised. For example, older adults with ID who receive services from a local authority. They face a contradiction because the aims of Norwegian policy include aspects such as independence, choice and dignity. However, all the underlying messages refer to them as being vulnerable and as being a burden to themselves, their service providers and the local authority (Hasler 2004).

An attempt has been made in phase one of the LSW program to be emancipatory. This process attempts to eliminate the causes of alienation and domination by, for example, giving a voice to older adults with ID who may be described as being ‘the marginalised and people who seldom make their voices heard in the society, or have such possibilities’ (Denzin 1991; Mertens et al. 1994; Myers 1997). The emancipatory perspective may also be related to the outcome of LSW, such as when storytellers give a speech to an audience about their life or when they share an album they have made with people they like.

The two concepts ‘emancipatory’ and ‘empowerment’ (2.2) have much in common. The focus in this study is on participants’ personal development. This can be seen as being an emancipatory process that can empower the participants to experience greater control in their lives, through gaining greater insight into how and why they have become the person they are today.

Mandatory provision and practices is another example. Persons with disabilities are protected by and benefit from the determination of individual rights (Söder 2009). Examples in Norway of the benefits of juridification include the right to have an Individual Plan and the mandatory provision of accessible information (2.3). Accessible information can, in this study, increase participant involvement and sense of achievement through receiving the same knowledge on the research and LSW as the others i.e. the interlocutors. This can give them greater opportunities to tell others about what they are participating in, which can give them a valued social role among those in their environment and in relation to research in general (2.2).

Rights and self-determination issues are well-known challenges in the provision of Norwegian local services for people with ID (Barne-likestillings og inkluderingsdepartementet 2013; Helsetilsynet 2006; Jacobsen 2007). Questions relating to storytellers’ self-determination opportunities and their right to the public services they receive may be seen as criticism of the local authority and service providers. According to Patton (2002) *“Such inquiry is aimed at confirmation and elucidation rather than discovery.”* (p.131). The storytellers and their interlocutors were, despite this, both asked questions that relate to this, because if we do not ask these questions, then we cannot collect data on self-determination, which is an important service-policy in Norway.

Other people's interest in the older adults and in their interlocutor's concerns, options and experiences may make the participants feel good and valued. This attention may also, to a certain extent, compensate for the dissonance of power created by attitudes about staff, the researcher's role/responsibility and negative attitudes to the part of our population with ID (Gibson et al. 2004; Patton 2002). The information provided by participants with ID to the researcher is treated as being as important as the information provided by staff. The 'voices' of both and what they tell the researcher about their experiences are equal. This seems the right way to go about a study that is based on requirements that are laid down in contemporary human rights (Goffman 1963; Hanley 2005; Johnson 2009; The Learning Difficulties Research Team 2006).

Equality is emphasised in critical realism and the researcher has an insider perspective (the same as IPA): *"viewing the knowledge of stakeholders as paramount in both understanding a programme and making it work, and thus engaging with them in developing a shared understanding…"* (Pawson and Tilley 2004: 12). One way to transform dependency is to give people with disability the same rights, the same opportunity to contribute to the information flow and to be heard and to act as any other citizen (Zarb 2004).

The epistemology and ontology that have been outlined above are selected parts of IPA and critical realism. This gives direction to design, which will be the focus of the next sections.

3.2 Flexible (qualitative) research design

The designs of this study are concerned with turning qualitative research objectives into projects. Critical realism and a flexible (qualitative) approach are both consonant with the view that it is research questions that drive study design. This also has to be linked to theory, pre-existing theory related to the development of research tools and analysis or new theory generated by the process of the research. Neither the critical realist view nor the IPA view has any problems with flexible design (Robson 2002).

> *"Because all methods of study can produce only approximations of reality and incomplete understanding of the phenomena of interest as they exist in the real world, the findings of flexible method research can be seen as no more or less legitimate than those of any other type of study"* (Anastas and MacDonald 1994: 60)

This research took place in a relatively 'unknown landscape'. It was therefore important to choose a design that *"…develops (emerges, unfolds) during the process of data collection and analysis."* (Robson 2002: 547). This quality of flexible design indicates a step-by-step process of stages with an explorative and descriptive phase before an explorative and explanatory phase.

Flexible design is almost exclusively used in studies with an explorative purpose. A descriptive and explanatory purpose makes use of both flexible and fixed design, alone or in combination (Robson 2002). Only flexible design is used in this study. A mixed design was explored but was set aside. There were a number of reasons for this, one of them being the lack of validation of schemas e.g. identity and ID (2.4).

It is not easy to provide a precise definition of flexible design. There is no unique single way of applying this (Huberman and Miles 2002; Patton 2002; Ritchie and Lewis 2003). There is, however,

a fairly wide consensus that it is: *"… a naturalistic, interpretative approach concerned with the meaning which people attach to phenomena (actions, decisions, beliefs values etc.) within their social world."* (Ritchie and Lewis 2003: 3)

According to Robson 2000, flexible design and qualitative design have the same meaning (p164). The term 'flexible' is preferred when a qualitative design incorporates quantitative methods of data collection (ibid). The term also refers to a combination of methodologies (critical realism and IPA), the designs used for particular purposes in this study (Delphi, participatory action research (PAR), pre- and post-interviews) and the triangulation of methods (Patton 2002; Robson 2002).

A number of options were available within this broad approach. One approach that was set aside was ethnography (3.1). An ethnographic study may be used in further studies of LSW, to provide descriptions and interpretations of the cultural and social structures that are related to people with ID. The main focus/objectives of this study are the impact of LSW and not cultural and social structures in a group. This is the main reason for setting aside this approach. The results of the analysis, despite this, do contain elements of ethnography.

3.2.1 Delphi approach

A *Delphi approach* is used in phase one to collect substantial knowledge about the phenomena, contexts, mechanisms and outcome of LSW. The Delphi techniques rely on 'expert' statements. In this study the 'experts' did not work in a group setting, which is more common in Delphi techniques (Dalkey and Helmer 1963).

They were instead interviewed individually and all had the opportunity to read and correct interview transcripts.

The purpose of phase one was to use the experts' experiences to develop predefined research tools for phase two (Øvretveit 1998). One aspect was to find similarities or differences in the practice of LSW and relate this to Norwegian services. Another was to find links between outcomes and the way the outcomes had been created (Delbecq 1986). This discovery-oriented approach was mainly emphasised in the first phase, to clarify whether a temporary planned phase two was meaningful.

3.2.2 Participatory action research

A flexible design that "… can generate sophisticated, robust and timely data and analysis." (Garbarino and Holland 2009: 26) fits well with the participatory action research (PAR) which aims to *"change social reality on the basis of insights into everyday practices that are obtained by means of participatory research—that is, collaborative research on the part of scientists, practitioners, service users, etc."*(Bergold and Thomas 2012: 6)

Representatives of the participatory research paradigm often stress the joint process of knowledge-production that leads to new researcher, practitioner and service user insight. These reflections are, from an action research viewpoint, not without consequences for people's everyday practices (Bergold and Thomas 2012).

These approaches open up for the use, in this study, of a number of methods adapted to people with ID (Myers 2009). They have been proven to be useful in understanding the experiences of people with ID and without ID (Bergold and Thomas 2012; Ellingsen 2010).

The existing situation for older adults with ID is addressed and also that of their immediate staff, to attempt to create a level of change (Ryan and Walker 2007). A phased approach is recommended for intervention (LSW) development and evaluation, to help the researcher to clearly define the process (Campbell et al. 2000).

3.2.3 Pre-interview, Intervention and Post-interview (PIP)

Phase two was, based on a participatory action research for the study of LSW, planned with pre- and post-interviews and an intervention between the two. The intervention (LSW) and data collection was adapted to the participants' ability to share their experiences of how and why LSW had an impact on some of the participants and not on others (Øvretveit 1998). LSW was categorised as a service, provided by first-line staff with a range of skills, training and formal education (Foster and Banes 2009; Haber 2006).

Some authors call this design a 'before and after interviews' approach. The approach in this study is designated PIP (figure 3.1), which stands for Pre-interview, Intervention and Post-interview. The PIP builds on dimensions identified in phase one and focuses on LSW context, mechanisms and outcomes/impacts for older adults with ID and their interlocutors. PIP requires not only a less flexible design, but also a more restricted data collection than is commonly used in qualitative research (Ritchie and Lewis 2003). The pre-interview may indicate stability and changes in the post-interview. The LSW process was explored in other ways. The LSW process did not require the comparison of pre- and post-interviews (Robson 2002; Øvretveit 1998).

The *intervention* is essential in this design. LSW does not work *"indefinitely, in the same way and in all circumstances, or for all people"* (Pawson and Tilley 2004: 3). It is important to attempt to find out what works for who and under what circumstances (ibid). Participants must therefore work with more or less the same framework to allow the participants' answers before and after LSW to be compared.

The impact of LSW was studied in a 'restricted situation'. This was defined as an eight to ten week period, with a minimum of one two-hour long meeting per week. This was set to make allowances for individual's availability and unexpected interruptions such as sickness.

The timeframes of the intervention/LSW were decided based on the literature review (2.4) and the researcher's experience with LSW (Westergård 2009). For example, it took Gibson et. al eight weeks to make a life story book. They concluded that they could easily and usefully have used more time on it (Gibson, Haight and Michel 2007). Lai and her colleagues used six 30-minute weekly sessions in their randomized controlled study and concluded that they had failed to accurately estimate the time needed for the intervention (Lai, Chi and Kayser-Jones 2004).

3.3 Ethical considerations

Ethical reflections in this study covers aspects such as recruitment, informed consent, data collection, presentation of data to participants, ownership of data (e.g. films) and the researcher's role. Ethical assessments were therefore made at each step of the research.

Assessment included aspects such as whether participants were affected, methodological considerations and whether the selected design and methods represented any particular ethical challenges (Ellingsen 2010). An important factor was the use of the researcher's experience to detect early signs of participant discomfort or feelings of being pushed into something they do not want to do.

The regulations, check-lists and guidelines that were used to ensure compliance with ethical consideration requirements are found on the following websites:

- University of Edinburgh
- National Committees for Research Ethics in Norway (Act of 30 June 2006 No. 56 on ethics and integrity in research)
- Statement from the National Research Ethics Committee for Social Sciences and the Humanities (NESH) (research on material of uncertain or unknown origin)
- Guidelines for research ethics in the social sciences, law and the humanities
- Check List for Research Ethics of Task Contracts (2001) (http://www.etikkom.no/English/Publications)

The following documents (only in Norwegian) have also been reviewed:

- Lov om behandling av etikk og redelighet i forskning og Forskrift om behandling av etikk i forskning (a law about integrity)
- Forskningsetisk sjekkliste utarbeidet av Den nasjonale forskningsetiske komité for naturvitenskap og teknologi (ethical check-list)

- Forskningsetiske retningslinjer utarbeidet av Den nasjonale forskningsetiske komité for samfunnsvitenskap og humaniora (general ethical concern)
- Retningslinjer for inklusjon av voksne personer med manglende eller redusert samtykkekompetanse (Regulations for including persons with no or diminished ability to provide informed consent) (http://www.etikkom.no/retningslinjer)

New procedures were issued by the University of Edinburgh during the field work. They were adopted in phase two, phase one already having been approved at this point in time.

3.3.1 National approval bodies

In phase one, it was ensured that participants' rights defined by the ethical and legal rules and regulations of the UK, Norway and Denmark were safeguarded. According to the literature review of ethical assessments (2008) and information provided by Professor Knut Engedal (25.06.09 - former manager of the Regional Ethical Committee Helse SørØst in Norway 'REK'), an ethical assessment was not required to be carried out in phase one because none of the 'experts' were asked to provide personal data about themselves or their clients. Only the University of Edinburgh assessment was required to be carried out.

In phase two, it was ensured that participants' rights defined by the ethical and legal rules and regulations of the University of Edinburgh and that apply in Norway, were safeguarded. The Norwegian REK Helse SørØst (http://www.etikkom.no/English/NESH) was contacted and ethical approval was requested. Their response was that ethical

approval was not required because the study did not contain personal data or new health or medicine knowledge.

A project notification was also sent to the *Norwegian Social Science Data Service (NSD).* Their response was that the University of Edinburgh was responsible for this research and that the required permits must be obtained from Scotland. The responses from REK and NSD led to ethical approval for both phases only being obtained from the University of Edinburgh.

The researcher was employed at the Norwegian National Advisory Unit on Ageing and Health most of the time this study took place. The Centre's regulations have therefore been followed.

3.3.2 Vulnerable participants and informed consent

Half of the Norwegian participants in phase two had an ID. They were therefore defined as being vulnerable in research and ethical terms (Corden et al. 2003; Kunnskapsdepartementet 2007; NEM 2005; NESH 2006). A number of difficulties were related to their disabilities. This included a higher risk of becoming sick due to their age (1.1.1). Planning for all situations that might occur was therefore not easy. The plan was therefore to tackle such situations if and when they occurred (see 3.7.1). One safeguard was a weekly follow up of participants through the weekly progress report (3.5.2). The researcher also had agreed with the manager what should happen if occurrences took place that were negative for the storyteller or for their interlocutor.

Decision-making and information were focussed on in this study. Participants were encouraged to take control of what they shared with

the researcher, in the questionnaire, in weekly reports, in interviews and video-recordings. They were also encouraged, at exchange meetings and before interviews, to think through what they wanted to share with others. The researcher never pushed participants to speak about things when they showed resistance.

One idea was to interview both the storyteller and the interlocutor together. However, after careful consideration including of the principle of retaining anonymity, it was decided not to use this approach.

It was ensured that informed consent had been given before conducting interviews (Crow et al. 2006). Authors disagree about the function of informed consent, about how or whether it can be obtained and practice is changing rapidly (Tinker and Coomber 2004). Informed consent has come to be regarded as a central element of ethically conducted research. The tests on www.etikkom.no were thought to be one way of testing whether potential participants had the competence required to provide informed consent. These tests are not well-known and are not highly rated. The National Committee for Research Ethics in Norway recommends that these tests are only used as a check list (www.etikkom.no). Others claim it is unlikely that any test can accurately gauge prospective participants' competence for a study better than the assessment of their understanding of that particular study (Ratzan 1980).

Ratzan also claims there is a notable lack of protection for elderly people used in research which benefits the next generation rather than themselves, in ethical regulations. The risk is particularly high for those living in institutions, environments that make them passive, indifferent to their own or other's welfare and reduces their autonomy,

so making it easier for them to become a victim of paternalism and overprotection (Ratzan 1980).

Whether the participants really understood the consequences of participation was an important question - the information they would be asked to provide, what they would be required to do, what they might get out of it, the contents of the study and its limitations (Ratzan 1980). The study was carried out in cooperation with a number of centres. The gatekeepers/managers at each centre considered these factors in consultation with the researcher and staff. The principles of informed consent this study safeguarded included an emphasises on that (Datatilsynet 2005; NEM 2005; NESH 2006):

- Information is given in a way that is in accordance with the person's capability to independently understand and agree to consent
- Information about the aims, risks and possible benefits of the research is given in advance
- The person should be supported by someone they trust in decision-making, who can independently confirm the level of the person's understanding and of independent decision-making
- Consent is based on a self-assessment and the assessment of someone they trust (see 3.4 & 3.7)
- The person is not seen as one of the many in a group with identical characteristics
- Gatekeepers at each centre know well those invited to participate. Gatekeepers and the researcher consider together how well qualified the person' is to provide independent consent and whether participation in the research would cause them any harm

It was important that prospective participants wanted to participate in the study. The decision on whether a prospective participant had the ability to provide consent was therefore taken at a meeting that included the prospective participant. They were asked whether they really had made this decision themselves a number of times during the research process, to ensure they really had decided themselves. Those weakened by illness during the work were supported by the interlocutor and gatekeepers in their decision of whether should continue or not. The researcher was informed of this decision after it had been made (3.7.1). Those participating had the opportunity to refuse or withdraw their consent at all stages (Crow et al. 2006).

The principle of informed consent requires that prospective participants are provided with information about the research at the point in time at which they were invited to participate. It also requires this information to be complete and accessible to participants.

Templates for 'informed consent', 'authorisation to hold personal data' and an explanatory note for personal research at the University of Edinburgh and Regional Ethical Committee (REK) in Norway (Regulation for including persons with or diminished informed consent in health research' (NEM 2005)) are easy to read for those who are good readers. Not every participant in this study could, however, read these documents. A template that had been used at the University of Edinburgh and at the Norwegian National Advisory Unit

on Ageing and Health /UAU[9] was adapted and was used in a step-by-step plan for obtaining consent. The following templates for informed consent were prepared for this study (translated for the thesis):

- The 'expert interviews' (appendix 1)
- For interlocutors (appendix 2)
- For people with ID (appendix 3)
- For film recording (appendix 4)

3.4 Sampling

None of the three sampling stages in this study are random. The data collected is drawn from a target population and much smaller samples can therefore be used to conduct in-depth investigations of data characteristics. This is also true for IPA studies, which are conducted on relatively small sample sizes (Smith, Flowers and Larkin 2009). Breadth of population coverage and statistical generalisability is sacrificed to allow in-depth exploration of the issues (Robson 2002).

A purposive sampling process was used, participants that are 'information rich' and 'illuminative related' to the phenomena central of this study were selected (Kemmis and McTaggart 2005; Robson 2002; Smith, Flowers and Larkin 2009). Purposive sampling aims to find insight and not generalisations that can be applied to the general population. It is therefore well known for providing useful

[9] UAU was a national program in ageing and intellectual disability in Norway from 2004 till 2007.

manifestations of the phenomena of interest (Patton 2002; Smith, Flowers and Larkin 2009).

In phase one, the idea was to gather data from more experienced practitioners of LSW and apply the data to research in Norway. According to the literature review, the UK and Denmark have more years of experience with LSW than Norway (2.7). When information for the three countries had been finalised, the question then arose as to how many 'experts' should be involved. Cultural influences in each country upon LSW could become clearer if more than one 'expert' from each country was included. The conclusion was, based on assessments of other studies, earlier experiences, similarities and differences between countries and concern about time, that two 'experts' from each country should be involved. Informants were recruited from the researcher's professional network.

The criteria for inclusion and exclusion in the sample for both phases were based on objectives and research questions, supervision from the University of Edinburgh and researcher's experiences. The inclusion criteria for '*experts***'** in LSW in *phase one* were that they:

- Are employed in services for persons with ID
- Have more than two years' experience in LSW
- Can use a LSW model and can explain it

The *exclusion criteria* for **'***experts***'** in LSW were that they:

- Had less than two years' experience with LSW
- Had only worked with children or persons without verbal language
- Did not work in day-to-day services

It was decided at the start of the study that two phases would be used. This was to ensure that sampling in phase two was not influenced by the results of phase one. Participants were recruited in meetings with housing and day centre staff and via announcements made during courses.

Pre-specifying the number of interviewees that would be included in phase two was challenging. One strategy that could be used was to keep going until 'saturation' was reached. Only a limited amount of time was, however, available. The number of recruits was therefore estimated based on experience from other similar studies (Atkinson 2004; Kittelsaa 2008; Morse 2000; Robson 2002). Between 30 to 83 participants were included in LSW studies in, for example, dementia care with designs that included pre- and post-interviews, tests and data collection using qualitative and quantitative methods and control groups (Gibson, Haight and Michel 2007; Lai, Chi and Kayser-Jones 2004). Morse (2000) suggests that the number of participants can be less than 30 if (Morse 2000):

- The scope is feasible
- The nature of the topic is obvious and clear
- The data are on target (i.e. they contain little dross and are rich and experimental)
- The study design produces more data per participants

Between two and eight persons with ID were included in qualitative studies that had been conducted in Norway (not of LSW, but studies similarities to this study), (Folkestad 2003a; Kittelsaa 2008). Nine service providers were included in one of these studies (Folkestad 2003a).

An estimated recruitment target of 10-15 pairs (i.e. 20-30 participants) was suggested at the start of this study. 19 pairs /38 participants were recruited, which was very satisfactory.

Pre-interviews were conducted over a longer period of time, participants starting LSW soon after recruitment. This meant that the researcher had the time to recruit additional participants after the first pairs had been started. This strategy did not influence other participants, the stability of the design or the data-collection. The process was clearly defined in advance and allowed the researcher to spread pre- and post-interviews over a period of time. This gave the researcher the time needed to give the participants immediate feedback on weekly reports and to follow up if they did not deliver.

The inclusion criteria in *phase two* for '*storytellers*' with ID were that they**:**

- Are aged 45 or more (no upper limit)
- Define themselves as interested and qualified to carry out LSW
- Have received municipal services for more than two years
- Have an ability and interest in telling stories from their own lives, possibly with the use of technical communication aids
- Are capable of giving valid consent to take part in this study

The *exclusion criteria* for *storytellers* with ID were that they:

- Are not able to communicate their life stories
- Have formally been diagnosed with dementia or severe psychosis
- Have carried out structured LSW within the last five years

Those included in the study had a number of different diagnoses and lived in a number of different types of residences, which therefore represent different cultures and welfare services. The most important participant criteria was that they had the capacity to provide informed consent and could tell a fully integrative life story. This complies with the ethical and legal rules and regulations of the University of Edinburgh and those that apply in Norway, see 3.3.1. The intelligent quotient (I.Q.) or degree of ID is not used in this study. This is due to the consensus arising from the extensive discussion on using IQ and degree of ID as criteria in studies, tests and services for people with ID (Fuchs, Deshler and Reschly 2004; Gjærum and Grøsvik 2002; Kylèn 1985; Swain et al. 2004; The Arc 2011; Walsh 2008; WHO 1992).

Persons with ID were invited to participate in this study if their manager, their gatekeeper (3.4 & 3.7.1), considers they are eligible to participate, i.e. are old enough (45 and over) and able to give valid consent (Smith, Flowers and Larkin 2009). Gatekeepers were mainly recruited from the researcher's professional network in Norway. Most were managers of local public services', housing or day/senior centres for people with ID. First contact was by telephone and e-mail. Some responded to informed provided about the project at conferences and some contacted the researcher and asked to participate.

Storytellers who had decided to participate were asked who they wanted as their interlocutor. The *inclusion criteria* in phase two for *interlocutors* were that they had:

- Worked in the service the storyteller lived in or received daily services from
- Worked a minimum of one year in this service
- Been asked to be an interlocutor by the storyteller

– Been approved by the leader of the service and for LSW as part of their day-to-day work

The *exclusion criteria* in phase two for *interlocutors* were that:

– The storyteller had not asked them to be an interlocutor
– They had a negative attitude towards this study in particular or to LSW in general

The most important staff criteria was that they were interested in being an interlocutor. Exclusion criteria were set to protect storytellers from difficult LSW experiences. The difference between an engaged interlocutor and a disengaged was important. A disengaged interlocutor could negatively impact outcomes and be difficult to detect. It was therefore important to screen out those who were disengaged.

3.5 Triangulation

The study was not based on a deductive model, but is built on existing knowledge, ideas, tentative theory and a conceptual framework (Miles and Huberman 1994; Ritchie and Lewis 2003). This implies that some research questions are determined deductively and others are left open to inductive analysis - open-ended questions and direct observation. Methods are applied to a specific locality and social setting, such as a day centre or housing centre for people with ID.

Institutional settings are thought to be a resource in story construction, but can also restrict what people feel they can say (Elliott 2005). Participatory research requires participants to be very willing to disclose their true views and experiences in LSW. A ‘safe space’ was

therefore needed to ensure participants felt sure that what they said would not be used against them and would not result in repercussions (Bergold and Thomas 2012: 13).

A participant's communication skills, including their' ability or desire to communicate, may also prevent them from responding. To gain better insight into this, the benefits of triangulation have been emphasised (Lesseliers, Van Hove and Vandevelde 2009). A Norwegian report on service quality for people with ID (RO-rapport 2006) and other researchers who work with people with ID recommend information collected as qualitative interviews combined with observations as the best approach (Ellingsen 2010; Folkestad 2003a; Kittelsaa 2008).

Concepts such as validity and reliability are approached by data collection triangulation (Gibson et al. 2004). Triangulation is used to strengthen the design and to reduce the threat of validity, researcher bias, respondent' bias and to obtain more reliable data. Triangulation also gives a more precise and consistent analysis (Blaikie 2003; Robson 2002; Øvretveit 1998).

The stories told by a storyteller and by the staff can differ due to them adding their own modifications and interpretations (Elliott 2005). This was an important issue to take into consideration. Storytellers and their interlocutors were therefore asked about their LSW experiences, which they conducted together. This provides a perspective that differs from that obtained by only asking the interlocutor and the 'experts' in LSW.

Pre-questionnaires and interviews are used in both phases.

Observations are only used in phase two. The design used methods from both ends of the naturalistic inquiry continuum; there are open ended questions and structured ones with elements of quantified data. The data collected is mainly qualitative. Textual data has not been quantified to any great extent to ensure that the understanding of phenomenon, from the perspective of the participants and their social and institutional context, is not overlooked or even lost (Kaplan and Maxwell 1994; Robson 2002; Smith, Flowers and Larkin 2009).

3.5.1 Pre-questionnaires and interviews

The pre-questionnaires used before interviews in both phases include open ended and fixed answer categories, to allow contextual data about participants to be collected (Archer 1995; Bhaskar 1998; Pawson and Tilley 2004; Wikgren 2005). Pre-questionnaires focus on participants' backgrounds as a person (name, gender, experiences) and as a social actor (any current work). This was collected to' give a better understanding of the data collected in interviews. The researcher also collected participants' addresses in phase one for sending interview transcripts.

The research questions and design of both phases imply a semi-structured interview guide, with a pre-specified order and question-wording (Ritchie and Lewis 2003; Robson 2002; Øvretveit 1998). Using an interview guide ensures interviews were research-driven, the focus being on the themes the researcher intended to collect knowledge on. Particular attention was paid to the participants' experiences with and perspectives on LSW (3.1.1) and the 'social reality' that influenced their LSW (3.1.2). Questionnaires were therefore both 'open' and 'closed', both exploratory and explanatory.

Some questions were also asked to compare pre- and post-interview data. There is a conflict here between IPA and critical realism. Combining the two, IPA reflecting process and meaning and critical realism reflecting LSW outcomes, is a useful approach.

A prerequisite for directly capturing 'participant statements about their thoughts, reflections, interpretations and understanding is that a "…research interview is an 'encounter', in which the listener accepts the story with complete respect and refrains from judging or evaluating it." (McAdams, Josselson and Lieblcih 2001b: 281). This is important, particularly in interviews with people with ID who often experience that other people 'speak' for them (Askheim 2003; Askheim and Starrin 2008; Atkinson 2004; Atkinson and Walmsley 2010; Ellingsen 2010; Gjærum 2010; Patton 2002).

Interviewees must understand the important vocabulary used in the interview and must be able to express themselves in a way that allows the researcher to receive the information they provide and interpret it correctly. Impaired cognitive function can make understanding complex questions and scope difficult e.g. the identity concept. Parts of the interview were therefore repeated in the phase two post-interviews, to test the value and validity of interpretations through noting unclear answers in the first interview being more clearly expressed in interview number two (Kittelsaa 2008).

The interviewees held an important stake in the topics covered in the interviews (3.6 & 3.7). They were therefore invited to comment on subjects that had not been considered and to ask questions (Smith, Flowers and Larkin 2009). It was clearly communicated prior to the interviews that the purpose of the interview was not to measure a participant's skills, as this could be a sensitive topic for some.

Normally a researcher wants the interviewee to answer spontaneously and to speak about things related to the question that they feel are important. Some people with ID may find this problematic. They may have difficulty sorting out essential parts of their answer and find abstract thinking and holding on to thoughts and information over time difficult. Some have difficulties with giving an overview, summarising and drawing conclusions. The communication challenges of some may lead them to pretend or appear to understand because they fear being corrected or reprimanded. Others may be afraid of saying what they really mean. Some may not trust and not feel secure in the environment and some may try to hide their disability and answer accordingly.

Their understanding (or presupposition) of their relationships with other persons with ID (as a social group) can be coloured by denial of their own handicap or reduced cognitive abilities (Ellingsen 2010). These difficulties can be challenging for the researcher. The author's position in this thesis is that failure to reach the 'truth' is not due to participants' lack of abilities but is due to the failure of the researcher' to achieve this. The researcher has a responsibility to ask questions that participants can answer, to prepare an effective data collection system and to find a way to help interviewees reveal their honest opinions. The researcher should ensure that every person feels that they are free to give the answers that they value and feel are truthful, even if the researcher finds this strange in the beginning.

Kittelsaa states that truthfulness is related to the way the researcher acts when interacting with informants (Kittelsaa 2008). The interviewer's power, the interviewees' vulnerability and the limitations and opportunities that result from this must be recognised (Kellett and Nind 2001).

An interviewee answering ‘Yes’ to all questions is a way of responding to the researcher’s power, to the asymmetric relationship. This type of response can be reduced if the researcher has sufficient ID knowledge and displays a respect and trust in the interaction and communication. This is particularly important when asking questions about self-perception (Folkestad 2003a).

Some researchers with experience in interviewing people with ID suggest that the researcher should (Ellingsen 2010; Sonander and Nilsson-Embro 1984):

- Have had some experience with people with an ID
- Have experience in interviewing
- Be mature and self-aware
- Be able to adapt to different levels of language
- Be understood as well as be able to understand
- Generate confidence and trust in interviews

The pre-questionnaires and interviews with storytellers in phase two were both completed using accessible text. Storytellers could also answer using tools such as scales that use symbols. Some questions relate to emotions. Simple drawings of five faces were used to answer these questions (appendix 5/only Norwegian text). These types of scales have been used in projects with people with ID before e.g. *The Maryland Ask Me Project* (Barret 2008; Bonham et al. 2004). The author also has positive experience using simple drawings to identify and express emotions in previous work with people with ID.

3.5.1.1 Piloting

Piloting and incremental plans were central to the research tools constructed in both phases of this study (Punch 2009). It was important to secure the collection of valuable data, to keep track of time so that interviews are predictable for the interviewee and to gain an impression of any environmental influences. Environmental influences were not always easily controlled.

Piloting of the questionnaire and interview guide were carried out, in phase one, by an experienced researcher and life story supervisor (twelve years ‘of experience). The conclusion was that the research tools worked well. The researcher also gained experience in dealing with potential environmental disturbances. Conclusions drawn from the pilot gave direction to phase one interviews and also assisted phase two.

The communication challenges experienced by many with ID makes the piloting in phase two of the two interview guides two especially important. The questions had to be unambiguous and concrete to prevent misunderstanding. The interview guide pilot for people with ID was carried out by a person with ID. A group of staff worked with the interview guide for interlocutors (see 3.6.1). The three first interviews with storytellers and interlocutors were defined as being a part of piloting, although they were analysed as a part of general data collection. The intention behind these ‘learning by doing’ situations was to develop good data collection plans (Robson 2002). The revisions made to research tools used to collect data were specified in a document titled; *Revisions of templates; information-sheets, pre-questionnaires, interview guides and weekly-reports.*

3.5.2 Self-observations and reports

Self-observations and reports from participants were used to evaluate the process, to encourage participants to reflect on the process and influence and support them in achieving a better understanding of LSW and a better conducted LSW (Robson 2002; Øvretveit 1998).

One self-observation situation was the weekly report written by both**.** A template was developed with accessible text and open-ended answer categories (see 3.7.2). These weekly-reports were requested to (Campbell, Stanley and Gage 1966; Cook and Campbell 1979):

a) Observe similarities and differences as the process progressed
b) Catch and eventually intercept serious problems and drop out
c) Prompt judgements on the influences of 'unintended intervention', such as unplanned events that result in changes in the participants` plan

Other observations were recorded by the researcher and documented in photos, small film-clips and field-reports from interviews in which participants show their products and closing parties (Robson 2002).

Observational method weaknesses include that self- reporting often focuses on the successes and not on the things participants struggled with (Øvretveit 1998). Video-recordings also raise an ethical concern, as they record private feelings or stories. Strategies to tackle these challenges were discussed with the participants before they started LSW.

3.6 Accomplishment of phase one – the preparatory phase

The nature of the data collection and analysis carried out in phase one was influenced by the amount of detailed information required to describe LSW elements. 'Experts' were asked in the pre-questionnaire about personal information and experiences with LSW (appendix 1). Experiences with LSW were further explored in the interview, which contained the following main topics (appendix 6):

- General experiences with LSW
- Description of the approach and the process in LSW
- Memories (related to storytellers)
- Influences (on LSW)
- Purposes and impact of carrying out LSW
- Challenges (related to LSW and participants)

A step-by-step-plan was prepared in this initial phase to safeguard ethical and practical concerns before data was collected (the process of sampling and analysis is not included in this list):

1. Based on the literature review of LSW; develop one pre-questionnaire and a semi-structured interview guide in English (appendix 1 & 6)
2. Obtain feedback from supervisors at the University of Edinburgh and make corrections.
3. Conduct a pilot with D.K, Edinburgh/ Scotland
4. Write a report and make corrections
5. Translate the questionnaire and interview guideline into Norwegian, with some adaptations for Danish. A qualified person checks the translations

6. Develop templates for informed consent in English; feedback from the University in Edinburgh and translation into Norwegian – as point 2 and 5
7. Contact prospective ‘expert’ interviewees (from researcher’s network) and send information about the study by e-mail
8. Enter agreements with interviewees and send e-mail; informed consent, topics in the interview and pre-questionnaire (appendix 1)
9. Conduct interviews
10. Transcribe the interview
11. Send the transcript to the interviewees; ask for additions, corrections and approval
12. Amend based on interviewees’ feedback
13. Translate the Norwegian and the Danish pre-questionnaire answers and interview transcripts into English before further analysing

A review of reflections from interviews was prepared based on field reports from both phases. These reflections were sought to ‘learn on the job’ and to improve the quality of interviews in phase two. The main issue in phase two was a serene setting in which to conduct the interview and thorough preparation. The researcher’s responses to the answers which interviewees gave were also carefully considered.

Phase one analytical work was completed (3.8.1) before phase two design was finally set. The results from the analysis were used to develop the research tools with participants in phase two.

3.6.1 Preparation of methods; a participatory approach

The participatory approach is used in phase one to create a design and method for phase two that respects people with ID and their service providers/interlocutors. This is based on an awareness that research on people is carried out with them if possible.

It is emphasised that the researcher and the participants play quite different roles (Söder 2009). The learning process involved not only benefits the researcher', but enables the participant to carry out LSW and reflect on their own resources. The participation of people 'may therefore be an empowering experience (Clarke and Keady 2002). There are further arguments for including participants (EASPD 2009; Kemmis and McTaggart 2005; Øvretveit 1998) such as:

- To increase the validity of the data and research results
- To increase sensitivity towards and capacity of identifying those characteristics that measure the impact on those who are most influenced, so that a comparison can be made with those who are not so influenced
- To endorse the moral principle underlying this work and the constant request from organisations that persons with a disability are viewed in the light of the phrase*: "Nothing about us, without us"*.

According to the Toronto Group (Hanley 2005), a good way to include people is to establish an advisory group and allow them to identify and prioritise the research questions. This was not possible in this study. A group of eight staff members and their manager at a senior centre for older adults with ID was however set up. The researcher also cooperated with one person with ID.

The staff group worked together, the cooperation with the individual person with ID being carried out separately. The objectives were defined before participant inclusion. Their experiences, concerns and priorities had therefore to be reflected in this. Maintaining a relationship of equal power between researcher and the advisors was arduous. It was also essential to maintain a balance between loyalty to the advisory group and the use of the most appropriate research methods. This was essential if a clear line in the collaboration was to be maintained (Hanley 2005).

An interview schedule adapted to interviews with people with an ID was drafted based on the results of phase one and the qualitative approach. This first step used pictures and simple words. The person with Down syndrome (TH, 56 years old), who the researcher knows well, was asked to supervise drafting. She reads and writes and conveyed that the suggested pictures were difficult to interpret. She suggested that they were used as answer alternatives. A drawing with five faces was also tested, which she thought was easy to understand. Based on her advice, a semi-structured interview guide skeleton was drafted. The pilot (3.5.1.1) for this draft was then conducted with her. TH told, in the pilot, of every word she did not understand and gave advice about words that could be used instead[10].

All information about phase two and the LSW book is written in accessible text. TH was the most important adviser to this text. She

[10] The pilot was actually also a starting point for a book we wrote together called *Friends*, which was published in 2014

wanted to be paid for her work with dinners, lunches and car-trips. So we travelled and ate while we worked. We also communicated by telephone because we live one hour by car away from each other. She had no desire to participate in this LSW study before she became an adviser. After this cooperation, she decided to participate.

The manager of the day centre for seniors had previously requested more information on LSW. We came to an agreement on this. They would provide advice on the interview guide for interlocutors and corrections of the book text and at the same time learn about LSW.

They worked in groups of three, each role-playing different parts of the interview. One asked questions, one answered them and one observed and noted the difficulties they experienced and the time they used. They provided feedback on this in a plenary session and wrote an observer's report. We, after this, went through the text of the LSW book on a big screen, so they could all comment on the re-drafted text. They suggested, from this work, the name 'interlocutor' for the staff person that supports the storyteller in their LSW.

The Delphi (3.2.1) and participatory approach means that the results of phase one consisted of:

- Two pre-questionnaires: storyteller and interlocutor (appendix 7 & 9)
- Two interview schedules: storyteller and interlocutor (appendix 8, 10)

- Four different information leaflets in accessible text [11]:
    - Storyteller (appendix 11)
    - Interlocutor
    - Their advocates and family
    - Others (staff/colleagues) in the residential or the day centre
- Three different templates for informed consent

Other results of phase one were a LSW book titled '*Life story work with help from an Interlocutor - A practical guidance with accessible text'*, which contained the following topics:

I. What is life story work?
II. Why should you carry out life story work? (Personal development, identity, life span)
III. Good ways to talk to each other (respect, talk about good things, talk about difficult things, encouragement and practical help)
IV. Getting help to tell your stories (agreement, plans for meetings)
V. Various ways to tell about your own life - benefits and challenges

[11] Due to the amount of appendices, only one of these is attached as an example

3.7 Accomplishment of phase two – the PIP

It was concluded, based on McAdams' publications, general LSW literature, epistemology/ontology and analysis of phase one data, that it would be possible to study context, processes and impacts of LSW and weight this towards examining personal experiences, knowledge and changes experienced by those involved.

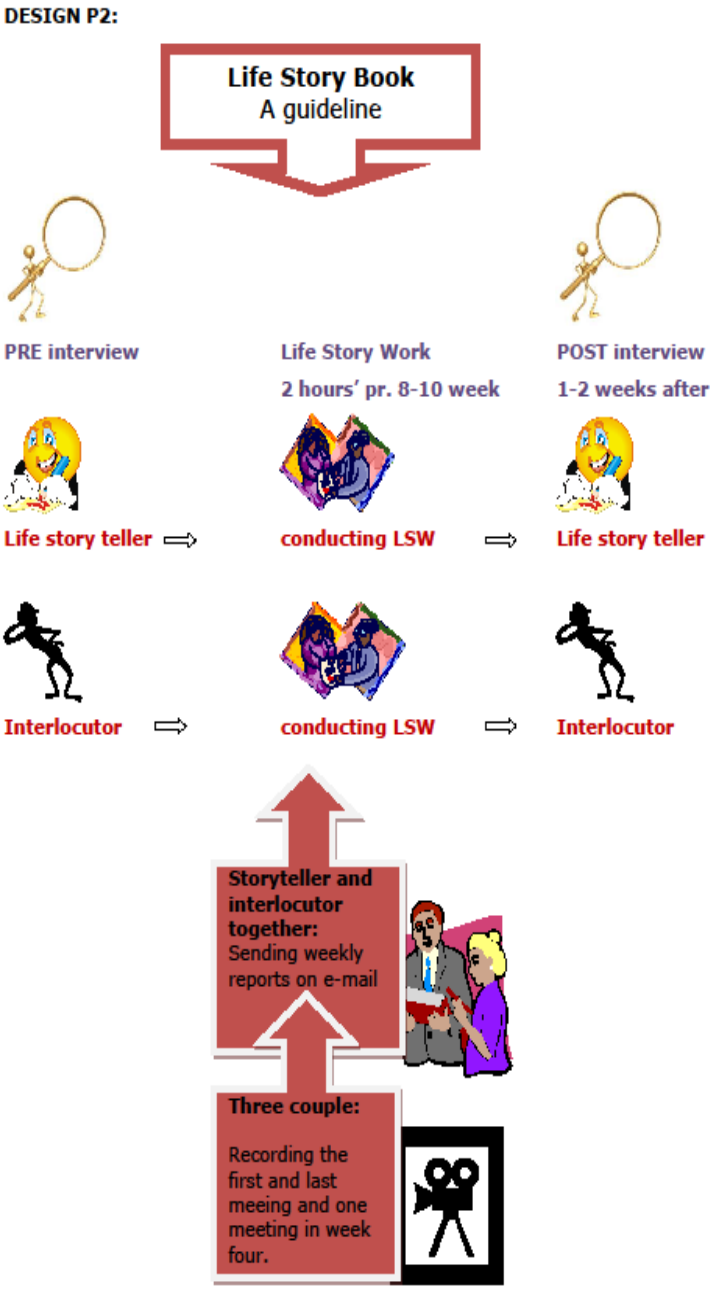
The purpose of the data collection in this phase was to seek new insights, knowledge and meaning by revealing stability and changes in all aspects of:

- The storytellers' identity/personal development, satisfaction and human rights
- The interlocutors' knowledge/understanding, attitudes and practice in central topics related to their work and PCA
- The participants' emotions, relationships and general experiences of LSW

The intention was not to ask questions which might capture deep psychoanalytic topics. This was not considered to be relevant based on the perspective of ethical concerns and the researcher's role.

Phase two LSW was fully defined and developed to avoid problems and confusion during the intervention process (Campbell et al. 2000). It was assumed that some changes would occur and can be seen in post-interviews. Essential experiences would also be recorded in the weekly reports. Figure 3.1 shows the design for phase two of the study.

Figure 3.1: A map of the participatory approach in phase two; 'PIP'



3.7.1 The obligations allocated to the participant and the researcher

The empowerment aspect is taken into particular consideration in phase two. Clear instructions on the self-determination of storytellers in the LSW programme were given to service managers/gatekeepers, interlocutors and storytellers. Those involved were assigned different roles and responsibilities as described in information meetings, information sheets and in the LSW book.

The literature review and interviews with 'experts' in phase one indicated that interlocutors might need supervision to help them deal with the emotional stress they might experience from listening to storytellers' life stories. Stories that were so painful that they might never have been told. Advice about how interlocutors (and storytellers) might handle such difficult situations was given prior to LSW being carried out and written down in the LSW book. Managers were also assigned responsibility for supervising participants when necessary e.g. if a storyteller needed psychological support due to connecting with difficult feelings. A plan for how the person would be taken care of was agreed in advance with the manager based on local solutions, local resources and what the storyteller wanted.

The *interlocutor's role* was different from the role they ordinarily had as front line staff, where they often took the lead when working with a user. Interlocutors were expected and required to be good listeners and that they encouraged the storyteller to lead the process and make decisions about their LSW. It was expected that they were good at asking questions and a patient listener, and have 'two ears and one mouth'; i.e. - listened more than they talked. Interlocutors were responsible for arranging meetings with storytellers and helping storytellers see the consequences of their choices.

However, they were not responsible for making decisions for them. They should advise the storyteller in their search to find out what he/she wanted to share with 'the world'. They also were required to alert the manager if abuse or other criminal acts were revealed, but always in consultation with the storyteller. This issue was included in the LSW book. It was clearly emphasised to all interlocutors that LSW is not therapy and that everything must be based on the storyteller's own decisions.

The first *storyteller' role* and responsibility was to decide whether the storyteller wanted to participate. When this decision had become clear in their minds and this decision was that they wanted to participate, then they had to decide which member of staff they wanted as 'their' interlocutor. The storyteller was responsible for deciding the length of the meetings, the location of meetings and how they wanted to carry out their LSW. All this was carried out together with the interlocutor, so that both were fully prepared. The storytellers also had to decide what they wanted to share and how they wanted to share it at the closing party. If a storyteller was weakened by disease or experienced feelings of lack of motivation during the process, then the interlocutor and the gatekeeper/manager helped them to decide whether they were able to continue. The researcher was informed if this situation arose.

The *researcher's role* was to be as independent and detached as possible, the main focus being on assessing the worth or value of the intervention (Robson 2002; Øvretveit 1998). The researcher was not only an investigator, but also a collaborator and facilitator. This fits well within flexible design and participatory action research (Bergold and Thomas 2012; Robson 2002).

3.7.2 Accomplishment of data collection

A step-by-step plan was conducted in this phase and in the same way as in the previous phase, to ensure ethical, reliability and validity conditions were met (Crow et al. 2006; Datatilsynet 2005; NEM 2005; NESH 2006; Ratzan 1980). The following steps were taken[12]:

1. Obtain manager approval of the research plan and of their role as gatekeepers
2. Prospective participants receive information sheets about the study and an invitation to the information meeting
3. Based on the inclusion criteria (3.4), storytellers ask one of their service providers to be an interlocutor; receive information about the study and a description of role and responsibility
4. Interlocutors receive a formal acceptance from their manager (before or after the information meeting)
5. Organise an information meeting with a predefined program and a separate meeting for participants to write the consent and fill in the pre-questionnaire
6. After the information meeting and before the first interview, the participants:
    - Read the LSW book, together or alone
    - Decide whether they wanted to self–observe via video-recording - if yes, they confirm agreement (appendix 4)

[12] Sampling (3.4) and analysis (3.8) are not included in this list

7. The researcher visits the interviewees at a location they decide and interviews them for 20 - 30 minutes (sound-recorded interview).
8. Any necessary adjustments are made after the three first interviews in the pre-interview with the interlocutors and the storytellers (3.5.1.1)
9. Each pair works for 8-10 weeks with LSW; this varies depending on how much time the storyteller needs to tell their story, the end-product which the storyteller wants to create and any other events which the interlocutor/storyteller might be influenced by
10. Submit with the participants weekly reports during their LSW
11. Conduct post interviews and provide video-recordings on a DVD[13]

In step 5, it was important that the researcher did not influence answers given at the pre-questionnaire stage. Storytellers who needed help were therefore encouraged to ask someone they trusted. In most cases this was the interlocutor they had requested. This situation was the starting point for cooperation between the two. Some interlocutors said they heard new things from the storyteller which surprised them. This resulted in some interlocutors becoming very curious about LSW. The pre-questionnaire that the *storytellers* answered contained

[13] First it was decided to send video-recordings by e-mail. But this could result in lack of anonymity. So it was decided that the interlocutor handed over the DVD in the post-interview.

the following topics (appendix 9):

- Names and addresses: age, gender and contact information
- Their home
- Which schools they had attended and the best place…
- Reading and writing
- Institutional life
- Work, day centre for seniors

The pre-questionnaires for *interlocutors* contained the following topics (appendix 7):

- Name and addresses: gender, working place, contact information
- Education and employment
- Experience with LSW

The interview situation opened new questions and enabled me to ask questions in an open way. It was important in interviews with interlocutors to make a clear distinction between experiences/ knowledge, behaviour and attitudes and take this into account (Ellingsen 2010; Robson 2002).

The main topics in the pre- and post-interview for the *storytellers* were (appendix 10):

- Collected memory and communication of life stories
- Social interests and networks
- Identity and self-understanding
- Quality of life
- Assurance and (self-) respect
- Self-determination and person-centred care
- Story telling

In post-interviews, storytellers were only asked about:

- Experiences with LSW in this project; observed changes
- Observed changes in the interlocutor during and after LSW
- Evaluation of the LSW process/program

The main topics in the pre- and post-interview for *interlocutors* were (appendix 8):

- Relationship with the storyteller
- Perceptions about the need of knowledge, positive attitudes and best practice in their work
- Perceptions about the storyteller's identity and personal development

In post-interviews, interlocutors were only asked about:

- The value of LSW
- Observed changes in the storyteller during and after LSW
- Own experiences of LSW: observed changes

The interviews were conducted by the researcher alone, supported by one service provider if the storyteller wished this. This was not necessarily the interlocutor. In one interview, the manager of the centre participated. In every interview care was taken to not overstep private boundaries. The asymmetry was more pronounced when a staff member was present at a storyteller's interview and it was then important that the interviewee did not feel inferior.

The researcher was prepared to cancel the interview immediately if anyone wished this or to take a break when wished. The interview situation was not very formal. The participant was to feel relaxed and safe and they had the opportunity to ask questions and receive explanations of things they wondered about (Ellingsen 2010).

An ‘expert’ (ex-4) gave some very good advice in phase one about interviewing people with ID, which correlated well with the researcher’s own experiences.

Each pair, at the end of each week of the LSW process, sent their comments and reflections in an e-mail to the researcher. General topics in the weekly reports template were:

- The plan for the LSW process
- Last week’s activities in the LSW
- What they talked about in meetings
- Experiences of telling (storytellers) and listening (interlocutors)
- Cooperation
- Motivation and challenges
- Other peoples’ reactions
- The use of the LSW book
- Resources (time, money)

The researcher read the report and answered the mail immediately. If the report had not arrived by the Monday of the week after, then an email was sent asking ‘what happened?’ Some interlocutors needed to be reminded that they were to write the report *together with* the storyteller and not submit a report *on* the storyteller.

Closing parties were a celebration of the completion of LSW (and post- interview). Participants had the opportunity, in these parties, to show the others what they had made in LSW. Storytellers, staff and the researcher planned this together and research funding was used to pay for food.

3.8 Accomplishment of the analysis

This section describes the analysis carried out in both phases of the study. Miles and Huberman state that the most important aspect is that the researcher is open and does not let anything limit the findings drawn from the collected data (Miles and Huberman 1994). Successful data analysis requires *"imagination, playfulness, and a combination of reflective critical and conceptual thinking"* (Smith, Flowers and Larkin 2009: 40). Data collection in phase one was carried out from 5th February 2010 (pilot) until the last interview on 19th August 2010. The data collection in phase two was carried out from 17th June 2011 (pilot) until the last interview on 12th March 2012. Table 6.1 shows all collected data from February 2010 to March 2012.

Table 3.1: Summary of the collected data

participants		pre-question	inter-views	weekly reports	film clips	pictures	field reports
P1: ex	6	6	6	0	0	0	6
P2: I	19	19	19+17* 36	148	2 meet. 87min. 13 clos. parties (5min)	36 prod. 13 portr. 40 sit.	71 inter-views 5:other **
P2: S	19	19	19+18* 37				
SUM	44	44……79 123		148	15 films, 89 pictures		82

*Explanations: P1/2: phase ½, 'ex': the 'LSW experts', 'I': interlocutors, 'S': storytellers. *Pair-13 did not complete their LSW, but a post-interview was conducted with them together.*
*Pair-19 did not complete the LSW, they only reported on one LSW meeting and just one conversation with the interlocutor was conducted. **) Contact with those who drop out and from three closing parties.*

The research data included the information sheets, PowerPoint presentations used in information meetings, the LSW book and the following objects[14]:

- Field notes
- Three different groups of pre-questionnaires
- Audiotapes, transcripts and codebooks from three different groups of semi-structured interviews
- Film-clips
- Photographs
- Data from correspondence: weekly reports in e- mails

The phase one analytical work differed from that of phase two. The structure of both was, however, the same. Data analysis was carried out to create a body of structured evidence through a series of steps, termed '*Analytic Hierarchy'* (Ritchie and Lewis 2003). This structure meets both IPA and critical realism analysis requirements. It also meets the design and research strategies of this study (Patton 2002; Smith, Flowers and Larkin 2009).

An account is given below of the different stages of the analysis and the researcher's experience with each stage.

[14] Numbers of sources in the objects are described in chapters 4, 5 and 6; about the findings.

3.8.1 Analysis of data from 'LSW experts'

The *Data management* process in phase one was as follows (QSR 2008; Ritchie and Lewis 2003):

1. *Data was sorted and synthesised* (in NVivo). A close line- by-line analysis of individual transcripts was carried out to identify perceptions and understandings and initial themes or concepts (labelling or tagging data by concept or theme)
2. An *index was created* (in Windows) by identifying emergent patterns and themes. This gave a survey of the questions that were dealt with; an index category and thematic category for each index category[15]. Themes and concepts remained close to the participant's own language and understanding by 'indexing sentences' verbatim from the transcript by using 'nodes[16]' in NVivo. The nodes reflected the index that was created. A decision was then made about which passages of the data related to parts of the index or nodes.
3. *Cross-sectional analysis*; the revised indexed data was imported to Windows[17] in a table function and sorted by theme or concept. A common system was devised for categories, chunks of original references in each node being placed into a

[15] The researcher had become thoroughly familiar with the data set through all the rounds with transcription and translation, so an index was easy to make.

[16] A node is a place to store data about ideas or themes that emerge from the analysis, and makes it possible to gather or 'tag' data sharing similar themes or characteristics (QSR 2010b: 11). This is similar to 'bracketing'.

[17] Because NVivo was a new experience, it was too risky to go further with NVivo in the analysis after the nodes were made.

column named ‘identified elements’. Key words were marked in bold font. This system was used across the whole data set and as a means for searching for and retrieving chunks of labelled data. This way of sorting data ensures that expressions are not removed from their context in a way that it is irretrievable and that others can see how the text has been abridged from the original transcript.

4. *The text was reviewed;* the extract of the reference (identified elements) was selected from the original expression. New text was found and sometimes the same expression was selected twice. Expressions that were also selected at other earlier points, were excluded (review/analysed twice). In some places the text, but not the meaning, was changed.

Some passages in NVivo contained references to more than one node/theme and were ‘multi indexed’, e.g. i) practical descriptions of LSW to be used in the LSW book ii) methods to encourage the storyteller and iii) communication techniques that are used to prompt the story telling.

Cross-sectional analysis gave a systematic review of the scope of the data. This was used to help find themes and examples which did not appear in an orderly way and to help manage the data in comparisons or connections in the next step of the analysis (Ritchie and Lewis 2003).

This next step was the *summarising and synthesising of data into a descriptive account* (Ritchie and Lewis 2003; Robson 2002) and was as follows*:*

1. A '*thematic chart*' or '*conceptually clustered matrix*' was created. Data identified by elements were placed into the chart. The references were retained within their context by the number of the interviewee, the theme and the language in which it was expressed.
2. The *index was revised* at the same time as the thematic chart was created and thematic categories were included. This gave a good overview of the topics contained in the collected data
3. The synthesised data was transformed into *descriptive accounts*, organized by topics in the thematic charts. The similarities and diversities of each theme were described
4. A *conclusion was made* which formed the basis for phase two

The thematic matrix makes the data more transparent. Phrases and expressions were retained as much as possible in the interviewee's own language, but not in the original language for the four interviews translated into English. The procedure in these interviews for verifying correct translation should ensure correct reproduction of the individual's expressions. It could not, however, retain the original expressions, which is the ideal (Ritchie and Lewis 2003).

The material from the stage before the conceptually clustered matrix shows the context of the expression. This was easy to find, as the matrix showed the identification-number of the interviewee and the index category. The reference to the timespan was automatically saved in the nodes for the interviews which were not translated, but not for translated text. This was added afterwards for translated nodes.

To save time, the reference system was identified using numbers for each interview and the index was connected to questions in the interview. Most of the examples interviewees talked about were retained in the first sorting/step of the hierarchy analysis model. The timespan reference or question number makes this easy to find and to use these examples in the descriptive part of the analysis (Ritchie and Lewis 2003).

Spelling errors in the original transcripts were corrected all the way from interview transcript to matrix construction without meaning being changed. The charts were critically reviewed one more time before the next step in the analysis was begun. Some of the thematic categories were moved to other charts and references were moved to other points inside the same chart. Almost every chart was changed and all references were counted one more time. This last procedure enhanced quality and made the analysis more accurate.

3.8.2 Analysis of data from storytellers and interlocutors

Many of the concerns in phase one were replicated in phase two, despite all data being analysed in NVivo 9. The stage-model used in phase one was used in phase two. An explanatory account (3.1.2.3) covering data for the whole study was however included (Ritchie and Lewis 2003). These phases were operationalised and roughly described in NVivo 9 through the following steps (QSR 2010a):

1. All data was imported into NVivo and *categorized* into different folders.
2. Data from Norwegian interviews and questionnaires were *transcribed and translated* into English in one process.

3. All data was *noded and aggregated* into ‘person’, ‘pre- and post-interviews’ and ‘pair’ and each case was analysed.
4. Thematic nodes were predefined and coded in a process (bracketing).
5. Based on an index of node-classification and attributes, data from pre-questionnaires, pre- and post-interviews and weekly reports were coded in a classification sheet and into four main thematic nodes relating to research objectives (1.5) and the LSW programme of this study. Definitions of attributes were based on respondent answers. Thematic nodes were grouped into data collected from a) interlocutors, b) storytellers and c) the pair.
6. Data in every thematic node was checked, revised and aggregated without changing the original text. Some thematic nodes were related to classification nodes of the same theme as additional information.
7. Lists of all nodes and classification attributes were made and organised into:
    a. demographic and contextual data about the informants
    b. the LSW programme
    c. personal strength of people with ID
    d. assumptions of PCA
    e. participatory development of research tools in this study

This means that all information/data from storytellers and interlocutors (incl. pictures and films), prepared individually or together (weekly reports/closing parties), were organised thematically in this coding’s list.

This strategy gave an overview of all data that had been collected and analysed. This made the descriptive stage easier, because themes could be ‘checked’ using the list.

8. The dataset was analysed in NVivo by creating models (p.5-16), using ‘queries’ (p. 27-54) and ‘visualizations’ (p. 57-69). ‘Reports and extracts’ (p.71-82) were also exported to word, printed out and used to write up findings. The systematic categorisation made most thematic nodes easy to read and summarise (QSR 2010a).

‘Query’ in NVivo, as ‘Word frequency’ and ‘Text search’, in most cases did not give good enough answers. Reading the text, asking about the meanings and making a summary was more useful. This approach was also used in phase one (3.8.1). The approach made it easier to find phenomena in each case and across groups of interlocutors and storytellers. All nodes and classifications were, at this stage in the writing up of the analysis, thematically merged into a unified text in the presentation of data and connected to the structure of the thesis.

The amount of collected data in this research meant that a strategy was followed to classify as much data as possible into different classification sheets with separate attribution values e.g. a person’s age and level of education or scaled responses such as ‘not agree, strongly agree’ (QSR 2010b). This was taken into consideration when questions in the interview were developed, as classification provides a means of recording descriptive data into e.g. node classifications. Node classifications with attribute values were made up of data from the pre-questionnaires, the pre- and post-interviews and weekly reports.

All data relating to interlocutors and storytellers were treated separately (case by case) in the analysis. Comparisons were then made to find similarities and differences that could explain variations in experiences/result of LSW. This was also related to PCA and the personal development of storytellers expected from the LSW programme. The following comparisons were undertaken:

1. Pre- and post-interviews of each storyteller and interlocutor; looking at change, experiential claims, concerns and understanding for each participant.
2. Pre-questionnaire and answers in the pre-and post-interview; looking for concurrence and gap e.g. how long an interlocutor had known the storyteller and if they recognised new aspects that changed their knowledge, practice or attitude.
3. Each interlocutor (pre-questionnaire, pre and post-interviews, photographs, film-clip) shows a profile of each person, giving a basis for comparison between interlocutors *).
4. Each storyteller (*).
5. Each pair (weekly reports); looking for variations in LSW processes and influences on this process.

One pair were analysed in relation to film records of two LSW meetings. The plan was that three pairs should record three of their meetings. However, only one pair had the opportunity to do this. The analysis of films from LSW meetings are therefore not included in the findings, even though they were transcribed and analysed in NVivo.

The photos and small film clips from the closing parties were analysed and categorised. Themes in the analysis were aspects of personal development, the relationship between the storyteller and the interlocutor and the process and products of LSW. Pictures from these

parties cover themes and content from the small film clip. Therefore only the photos are used in this thesis.

3.9 Summary

Analytical work methodologies, design, data collection and strategies aim to match the opening statements on perspectives, purpose and objectives of this study. Critical realism and IPA underpin exploration, meaning-making, description and explanation of the essence and the value of LSW. The IPA position is used to strengthen the subjective perspective of participant experiences of personal development related to LSW. Critical realism is the conception of a stratified social reality, an awareness of the importance of contextualisation, explanation mechanisms and the relation between structures and agency. The relevance and usefulness of this is emphasised in this study, based on participant experiences of LSW from a subjective, a social/structural and a practical perspective/level (Lesseliers, Van Hove and Vandevelde 2009; Smith, Flowers and Larkin 2009).

The participatory nature is a significant aspect in this study. The approach may lead participants to feel valued and encouraged when the researcher opens up their own reflections and new lines of enquiry to them. The learning process not only benefits the researcher but also the participants, who learn how to conduct LSW and reflect on their own personal development. People's participation may therefore be an empowering experience (Bergold and Thomas 2012; Clarke and Keady 2002; Kemmis and McTaggart 2005). The older adults and their facilitators are given a 'voice' and may feel good because of the interest of others in their concerns, options and experiences.

Chapter 3.2 reviews how research questions are turned into participatory action research. It also reviews why the research is divided into two phases, data collection triangulation being carried out in the second phase. This section explores the actualisation of a flexible research design, an initial phase (phase one) as a basis for pre- and post-interviews and a LSW programme as an intervention (in phase two).

Ethical considerations, sampling processes and inclusion and exclusion criteria are important issues at this stage in both phases for the three groups of participants (‘experts’ in LSW, storytellers and interlocutors). This study is too small to say anything about regularities. A desirable end-state is to therefore to come up with one or more postulated answers about *“What works for whom in what circumstances and in what respects, and how?”* (Pawson and Tilley 2004: 2).

There is a paucity of research in the context of LSW and older adults with an ID in Norway. Information from the ‘experts’ and the researcher’s own experience therefore become important. The first initial, explorative phase with ‘experts’, who were knowledgeable about the phenomena, setting, mechanisms and contexts that appear in LSW, were central to phase two. It is emphasised that a preparatory phase/phase one not only involves collaboration with well-educated staff, but also collaboration with people with ID as experts on their own lives. This element of critical theory and IPA is recurrent in this study.

The characteristics and the methods of qualitative research support this study. A pre-questionnaire and interviews are used in both phases.

Weekly self-reports submitted by e-mail and self–observations by video recording are also used in phase two to capture a consistent and integrated set of statements and to which responses are made (Blaikie 2003; Øvretveit 1998).

Informed influences are also described in this section: the values the researcher holds in the choice of research area, how questions and design are formulated, choice of collection methods and techniques, and interpretations and analysis (Bryman 2004).

The design and methods that were developed were planned step-by-step. The analytical work was also structured in accordance with a well-recognised method. Technical reports were written on data management, translations and analytical progress in and outside of NVivo.

This section refers to a number of appendices that contain papers that were not included because the thesis word limit would be exceeded. One of these is the LSW book/intervention developed with the participants and written in accessible text. The appendices that have been included relate to the research tools that were developed; templates for consent, interview guides, an example of accessible information about the study.

The content of this section links to the next section on descriptions and observations of life story work collected from the 'LSW experts', and to the two subsequent sections (5 & 6) on findings.

4 Descriptions and observations of life story work collected from the ‘life story work-experts’

Data on the importance and the impact of LSW was collected from the six ‘life story work (LSW) experts’ in phase one (Delphi approach). LSW programme development topics are mainly based on literature reviews (2.5 & 2.8).

This section describes the emergent patterns, key themes and observations drawn from the analysed experiential material provided by the ‘LSW experts’.

The first section (4.1) contains information on the participants’ demographic and contextual data. It shows the richness of their LSW experience. The next section (4.2) contains statements and examples of the importance and usefulness of LSW. This is followed by a section on the impact LSW has on storytellers (4.3) and the impact LSW has on staff (4.4). A summary is finally provided (4.5).

The structure of this section reflects the relationships between themes that emerge from ‘LSW expert’ experiences. Sources of data are pre-questionnaires and interviews.

4.1 Demographic and contextual data about the experts in LSW

This section outlines the importance of the demographic and contextual data provided by the participants in phase one; their background, relevant skills and any preconditions for taking part in this study.

The table below, and table 5.1 in chapter five and 6.1 in chapter six, are based on the arguments found in guidelines presented by the 'Ad Hoc IASSID Working Group on Aging-Related Demographic Studies': *"…contextual variables (culture, ethnicity, SES, etc.)… have an ostensible bearing on the outcomes or results, such factors should always be defined as much as possible, so as to advance comparability and replicability."* (IASSIDD 2005: 59). See the table on the next page.

Table 4.1 below shows the range of 'LSW expert' experience. They had on average 22.5 years of experience in services for people with ID and a range of backgrounds and former positions. This represents a good knowledge basis for working with LSW. LSW experience, which did vary from 1 to 37 years, was however valued as a good start and basis for the study.

The 'LSW experts' were very engaged and interested in people with ID and their living conditions. One example was LSW expert 1 (ex-1) who stopped working as a manager in the municipality because she thought it was more important to work directly with people and their life stories. When she talked about her work, silent tears ran down her cheeks. She was deeply touched by the stories they had shared with her and how their life had been changed by LSW.

Table 4.1: The 'LSW experts' personal attributes and experiences (N: 6)

theme	***characteristics and experience***
sex	3 female 3 male
countries	2 from each country; UK, Denmark, Norway
educational background	learning disability nurse, social worker, master in social work, social educator, family-therapist, preschool teacher, pedagogue
current position	puppeteer and story gatherer freelance consultancy, director of information strategy in a NGO for people with ID, senior municipality consultant, educational consultant, retired/institution managers
numbers of years in services for pwid	15 - 37 years; in total 135 years; average 22.5 years
number of years working with LSW	1 - 37 years; in total 101 years; average 16.8 years
user-groups with whom they have conducted LSW	people with: ID (6), - mental health needs (3), - physical disabilities (2), - dementia (1), staff and people from the general public (3)
age groups – users	youth (3), adults (5), older than 45 years (5)
storytellers' placing	institution, private home with families or alone/personal budget, public accommodation with public services and day services
the experts' experience in LSW	teaching (3), facilitating people with ID to perform public speeches about their lives (2), puppet show based on peoples' life stories (1), developed exhibitions from earlier central institutions (2), indirectly as managers (2), innovative computer based individual planning, based on more than 15 years` experience with LSW (1).

4.2 The usefulness and importance of LSW

Some 'LSW experts' said (in phase one) that LSW was one of the best things to be involved in within services for older adults with ID (ex-1, 5). LSW is, however, not easy for people in their 20s, as they are often too close to their feelings from childhood and the work maybe experienced as being too traumatic for them. The advice was to start somewhere in middle-age, because at this time people start to see connections and patterns in their lives (ex-1). One informant (ex-3) told about two different situations of the usefulness of LSW:
Example on letter d):

> *"I think it was two days before he died that I came to visit. He had his eyes closed so I did not know if he was conscious or not. A young man sat beside his bed. I wanted to be alone with NN, so I sent the young man out to drink coffee. But he was soon back; he was of course paid to stay there. He was NN´s guard. My thought was that I wanted to do something both for NN and for his guard, so I found NN's photo album and placed myself so that he also could see the pictures. I talked about things that had happened, who the people in the pictures were and the things that NN had told me about. He learnt a lot about NN, which was important, because he was going to sit there and needed something to talk about with NN. I don't know how much NN grasped from it, but it seems that he grasped some of it. Sometimes I think I saw him blinking his eyes. And it was a really good time we had together. I believe it's very important to talk to the person who is on his way over."*

Example on letter h)

> *"There have been 'war-children' (children of German fathers and Norwegian mothers) at NN. At G… (one of the orphanages organised by the Germans) there were around 20 'war-children' who collectively had been diagnosed as being intellectually disabled. Some of them had an ID, but not all. Most of them had no contact with their mothers. Most of their mothers were married to a new man, who they hid their story about the child from. My story with one of these children started when he was an adult man with a very challenging behaviour; he was extremely self-injuring. According to Responsibility Reform he was supposed to leave the institution; the question was whether he could move to the municipality where his mother lived with her new husband. They had not had any contact since she left him at the orphanage and the staff agreed that they could not do this to her. But, I wrote a letter and she called me after some days. For the first time she told her story to her husband, who responded by saying: "Of course we will take care*

of your son". I remember, I was so nervous at that time. I had sent the letter in an envelope without any institution markings. I was so happy for the lovely end of this story."

This story relates to 'war-children' (1.2), a painful topic in Norwegian history. More data about the situation of 'war-children' could not or was not considered to be relevant to collect in this study. These children are now old and data collected on this topic is only used to provide examples of the usefulness of LSW in different situations.

Most 'experts' emphasised how important knowing their background is to people. Some people with ID are not able to grow personally until they have an overview of their lifespan and social network.

Most 'LSW experts' said 'their' clients preferred to talk about their past, especially the oldest ones (ex-1). One 'expert' however reported their clients talked as much about the past as about the present and future. Storytellers could also remember more when they told their stories to other people who had the same experiences (ex-3).

4.3 The impact of life story work on service users personal development, as reported by the experts

Analysis of the data provided by the 'LSW experts' shows that LSW has an impact on storytellers' memories, emotions, empowerment, initiative, communication, health, happiness, attitude, competence, relationships and other factors that may be described as issues related to *personal development.* This is elaborated further below:

- *Memories:* storytellers' start to remember stories; their stories, their memories, emotions and their perspectives on their own life start to change. They start to remember not only the hard things, but also funny things.

- *Emotions:* users, when they feel they can trust the interlocutor, often show anger, sadness, regret, happiness, joy and excitement. These emotions, and their expression, arise directly from LSW and give them a 'boost'. They express well-being, satisfaction and pride. People relax, reveal their true self and can truly sparkle.
- *Empowerment and initiative*: storytellers become empowered and take action on behalf of themselves as a group. They take more control of their lives and they think more about who likes them and who they can ask for help. They start to work with their memories and life in general; they take initiative and their self-determination grows (the pedagogues report that the residents become more demanding, see 4.4). They feel more important and powerful. They feel respected and valued. Other people are more interested in them and LSW may help them when they apply for a job. What they learn in LSW may also help them to be more independent.
- *Communication*: communication increases. More verbal and nonverbal communication, they speak more and talk in greater detail about things than before. There are more meaningful conversations. LSW lets them show how good they are at giving speeches. Staff also understand how the use of an interactive CD on the computer can help people present themselves[18].
- *Health and bereavement*: storytellers may have pictures that can help them remember and grieve over a person who has died. Those

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[18] *Show what they want to achieve, what their concerns are, what their fears are.*

who took part in LSW are acting in ways that result in their individual needs being better met and therefore a better life. The older adults reduce medicine usage and are more harmonious.

- *Personal development/personal growth*: LSW creates, promotes and develops self-identity and confidence. LSW also appears to give those involved in it a better understanding of their life and themselves. They may also be able to cope better with the things that happen in their lives. LSW helps them to grow up, become an adult and take greater responsibility for themselves (see above; ex-2). They have more self-confidence after LSW and they may find other or a new focus in their lives; greater self-esteem and greater openness towards others[19]. LSW helps people define their own life goals and wishes[20].

Examples the 'LSW experts' told about include:

Ex-1:

"It is important that older adults with ID feel free and move onwards in terms of being able to see the patterns in their own life (LSW); make sense of what's happened to them, and understand how our time creates a basis for deciding things they were not able to do before, because people's attitudes were different then and they were living in institutions where people told them what to do."

Ex-2:

"…it's more significant that LSW contributes to people becoming more... what is the word...becoming more of an 'adult', taking more responsibility for themselves, which is… you know... there is no scientific study on this, but all this work about encouraging individuals to take responsibility and understand who they are and how they got there, is the making of an 'adult'… They never had a life as an adult in

[19] Expressions change from being 'stone faced' to become trustful, curious and open, but it takes time - 6 years for one person.

[20] They need a lot of help to be concise about life goals and wishes.

their previous life. Maybe if they had a small job, they might have become engaged in a more mature way. We have seen much evidence of that. And I would say LSW and person centred planning may contribute to that crucial development into a mature adult."

Ex-5:

"…people have lived for 40-50-60 years without knowing their life. Neither do we. They have no family, they have nothing. They don't have any contact with their family and no history to tell. They have no sense of their own history."

When the 'LSW experts' were asked to tell a sunshine story related to LSW and personal development, ex-5 said:

"Michael is 35 years old and he has autistic traits, but we are unsure whether he is autistic. When his favourite service provider was coming to work on the next day, he always took down the picture of her from the board and say: 'no, she is not coming, she is sick'… When we asked him, he wanted to come with us and make a book with pictures from his life. He and his pedagogue took a day off to take pictures of an orphanage where he lived for the first ten years of his life. When they arrived, he simply didn't want to get out of the car. The pedagogue told him that: 'you can stay in the car if you want. You think we are going to move you back to this place, but we are not, we will take you back home. We are only going to take one picture for your book'. After the picture was taken, they were sitting in the car when he said 'do you know KH?' The pedagogue answered 'no', although she did because she had read in the case papers that KH was his mother and had read that he knew his mother when he lived at the orphanage. When he asked her if she knows his mother, she told him no, because she was afraid. When they came home, and were about to put the picture in his book, he threw the book onto the floor. He didn't want to make anything in the book. The pedagogue came to 'me' and said that he was totally crazy, she said: 'I've lied to him and he knows it because he refused to create anything in that book, what can we do?' We had a supervision meeting and discussed whether we should contact his mother. We found his mother with the help of a television program called 'trackless'. She did not live far away and said she would love to meet him. It was written in the journal that she had been advised to keep away from him; because he could not manage… he cried every time she walked away… this happened 25 years ago and now she wanted to meet him. They met a few days later. He has eight siblings, he visits his mother at weekends every fortnight and he works happily with his life story. That is really a sunshine story. He also continued to take down the picture of his pedagogue. He loves it when she comes to work and she is never sick any more when it is her time to be on duty. His autistic traits almost disappeared. He was not autistic; he had been grieving and was anxious because he had been left. His reaction to this was to withdraw into himself and we therefore thought he was autistic. No, he is not autistic, he just missed his mother."

This shows that LSW provides services with a means of stimulating peoples' personal development and, through this, help them to feel the strength they need to live the life they want and to be able to tackle the situation they are in because of their disability better.

4.4 The impact of life story work on staff

Most 'LSW experts' (83%) reported that the staff viewed the storyteller in much greater detail after LSW. They could see more of the 'real' person and did not take the service user for granted. They were more understanding and had more insight. All 'LSW experts' (100%) said the staff changed practice after gaining knowledge about the storyteller (N:6). One of the 'LSW experts', who had been teaching and facilitating LSW for more than 25 years, said:

> *"We (i.e.; the staff) have changed ourselves. Suddenly, we don't hear so much at staff meetings and suddenly the person is not so problematical for staff, because we now look at them in a different way."*

Some of the general changes in the staff group the 'LSW experts' spoke about were;

- They have more *insight and understanding*; better 'access' to the service user. They know the person in another way than before and so have a better knowledge base from which to provide a qualitatively better support. They know more about how to engage and encourage the service user.
- They *accept and believe* in the user's choices; they are more confident, which reduces the risk of failure in practice
- They change their *practice*; they are with the service users in a different way, which provides more effective support to the service user's life situation

- They have more *attention and respect* for the service user's private life. They are more aware of what appear to be 'commands', making it is easier to resolve conflicts; they know much more about the service user's boundaries
- They are better able to *support* the service user in remembering things and now view this as a more important part of their work
- They now do *not work according to their 'standard routine'*; they improved their professional skills because they are more curious and read more specialist literature

The 'LSW experts' said the staff's *initiative* changed during and after LSW*;*

- They were more interested
- They 'fight' more for the service users by talking about their life
- They are encouraged by their work
- They spend more time with the service user and are more involved in the service user's future life situation
- The 'LSW experts' said that LSW changed the way staff *communicated*;
- They felt more confident about having a conversation and sharing stories with the service user
- They had more topics to talk about and had more meaningful conversations
- They felt more confident about interpreting what the service user tried to communicate

Changes in *relationships between the listener and the storyteller* was another aspect 'LSW experts' spoke about;

- LSW builds/promotes a relation and it strengthens the relationship between the staff member and service users
- LSW is a 'vehicle' for good interaction
- The quality of a relationship also determines the quality of LSW; a life story does not just 'automatically' come
- The relationship is mutual, making it easier to resolve conflicts
- The relationship becomes more individual and improves during LSW
- The staff and the service users interact much more, they meet each other with a common interest in the service user's LSW
- LSW improves the feeling of common experiences and a shared reference frame

The changes in *attitudes among the staff* which 'LSW experts' spoke about included:

- Their attitudes became more positive
- They gained more respect for the storyteller e.g. ex-4: "the person is not an object of nursing care, but the owner of their own life."
- They have more things in common and feel more like a fellow human being, staff also feeling more equal to the service users
- They do not take the service user for granted
- The staff change their perception of 'the best solutions for everyone' and 'how difficult a person is'; they discuss things more with the service user and they are more aware and listen more carefully
- They are surprised; some staff were impressed by the personal strength which some service users displayed

- The staff are very positive about LSW, they are excited and enthusiastic, their emotions and enthusiasm influencing others because they are so happy about it (see 6.2.3)
- The staff are proud, e.g. ex-2: *"they feel they have helped someone to take more action in their life!"*

The 'LSW experts' spoke, in phase one, about listening to others' life stories being a hard and emotional task e.g.

Ex-1:

"After these stories, sometimes I would feel just very sick, very angry, very depressed."

Ex-3:

"It affects the staff in the same way as it affects the storytellers."

The findings in this section indicate that LSW inspires staff to work in a person centred way. Learning about a storytellers' life can give a greater understanding of the importance of working in a person centred way and can result in staff feeling more comfortable and related to those they work with. They no longer take the service user for granted. Staff change their practice, their attitudes and learn more about the service user's life. This 'circle' of learning from each other in LSW is discussed in more detail in 7.3.1.

4.5 Summary

Chapter four outlines the findings of the examination of the variations and benefits of LSW. The 'LSW experts' spoke about how important it is to staff that service users get to know their stories. So was gaining more knowledge about the persons they work for.

Demographic and contextual attribution, related to phase one samples, were reviewed in the first section. The samples show the variation in gender, cultural background, ages, education and roles. It can be said that this variation is representative of services for people with ID.

The informants' experiences show the themes that may arise in a wide range of LSW approaches - not just those that arise in the approach used here. The data in this section formed an important basis for the phase two interviews. It also creates a basis for the participant experience outlined in chapters five and six. These represent the contextual data and 'driving mechanisms' behind the evident data on participants' LSW experiences.

Section 4.4 contains statements from the 'LSW experts' on the impact of LSW on staff. They reported that they viewed the storyteller in much greater detail after LSW.

The next section relates to the storytellers who took part in the LSW programme. LSW is the phase two intervention in this research work (3.2.3 & 3.7).

5 The storytellers' experience with life story work

This section describes the patterns, themes and observations drawn from the analysis of the experiential material provided by storytellers. The first section contains demographic and contextual data (5.1) on the participants, which creates a basis for the exploration and explanation of the impact of LSW. The next section (5.2) contains LSW structural and practical condition findings; both contextual data and data that may identify mechanisms and impacts of the LSW programme. The section contains storytellers' descriptions of conducting the LSW viewed from their perspective. Section 5.3 considers the impact LSW had on storytellers' personal development; how they changed and how this may be understood. These impacts are fully described in the following sections. The impact of LSW, particularly on storytellers' personality and identity development, is described in section 5.4. This section illustrates the relationships between the themes that emerge from storyteller LSW experiences.

Sources of data in this section are: pre-questionnaires, pre- and post-interviews, weekly reports written by storytellers' and interlocutors together, the researcher's field notes and observations and pictures from closing parties.

5.1 Demographic and contextual data on the LSW storytellers

Storytellers answered the pre-questionnaire in the information meeting with help of someone they trusted (3.7). Those who dropped out before they finished their LSW are therefore also included in tables 5.1 and 5.2. Questions that were not answered are not included.

Table 5.1: The storytellers' personal attributes and experiences before life story work (N: 19) (%)

theme	***characteristics and experience***
sex	14 female (74) 5 male
distributions	12 from a city on the west-coast (63) 7 from cities in the south-east
accommodation	17 lived in publicly owned live-in support, shared/group homes with apartments or rooms, often with common rooms (89)
public services	11 went to a day centre[21] (58)
education[22]	15 persons had attended primary school 13 persons had attended secondary school 10 persons had some form of high school education
schools	11 had only attended special schools (61) 6 had attended both ordinary and special schools* 1 had attended ordinary school only

[21] In one case, senior centre staff from users' housing followed them to the day centre, while in another senior centre staff are employed only at the centre.
[22] Storytellers may have attended both primary and secondary school.

*work**	12 had only done sheltered work (71) 2 had done ordinary work 1 had done both sheltered and ordinary work 1 had never worked
institutions **	12 had lived in a HVPU-institution[23]: 7 had lived in one, two or three institutions, 5 had lived in more than three different institutions (63) 6 lived in their family home 1 could not remember
*age when they moved to the institution**	5 moved when children: the youngest was 4 years old 1 moved during adolescence 2 adults: a lady 45 years old, moved in because her mother died 3 could not remember
reading, writing skills and interests	10 could read (53) 5 could not read 3 could read single words and symbols 1 was blind but likes to be read to. He was the oldest 1 likes to be read to 6 like to look at books with pictures 10 like everything: books with text, watching movies, reading newspapers etc.

*The three youngest were 16 years old when they started work. One of the oldest ladies had lived for many years in an institution and had worked without payment. She was 45 years old when she was first paid for her work. There was an even distribution between those who had retired before the normal retirement age (67 years) and those who

[23] Helsevernet for psykisk utviklingshemmede (HVPU) is a governmental organisation of Norwegian central institutions for people with ID. It was closed in the early 1990s.

still worked full or part-time. The average age of those who still worked was 58.6 years. The oldest was 69.

**They had, on average, lived for 24 years in an institution. Five had lived in an institution for more than 20 years, one (man) for more than 39 years. He moved in when he was six years old and moved out when he was 45 years old. A woman had moved to the institution when she was 35 years old and moved out when she was 60 years old (25 years). Most storytellers did not want to talk about their experiences from the institution, both good and bad. Only some said that always having people around them was a good thing. One said *"There was never peace, I could never be alone"* (S-11). Some liked the work they carried out at the institution and the swimming pool. Others missed having their own kitchen and bathroom.

Table 5.2: Distribution of storytellers by age groups (N:19)

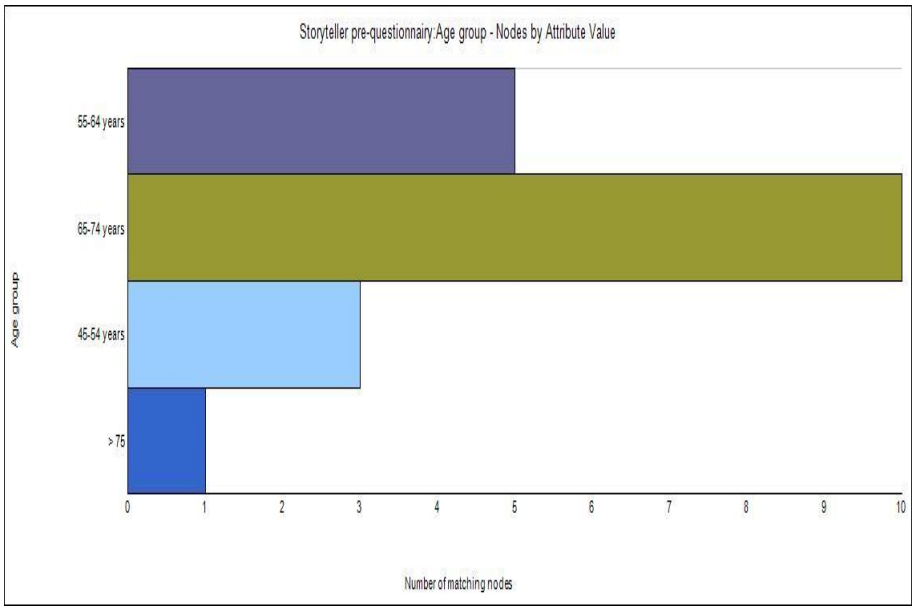


Table 5.2 shows that the majority of storytellers were from 65 to74 years old (53%). The men were on average five years older than the women. The staff had, despite this, on average known the women 1.2 years longer than the men. The two youngest, both 49 years old, were women and the oldest was a 78 year old man. The average age of the storytellers was 63. The average for the men was 66.8 years (ranging from 57 to 78) and for women it was 61.7 years (from 49 to 71).

56% had told staff about their life stories prior to this work. 44% had not (N:18). Contextual data on interlocutors experience with LSW (6.1) and storyteller findings show that LSW was a new experience for most of those involved. The findings also show that they meet the study's inclusion criteria.

5.2 Storyteller experiences with the structural and practical conditions of the life story work programme

Data collected from participant evaluations of the LSW programme (the LSW book and the organisation) are not included in this thesis. It contained too much material and will be the subject of subsequent publications. The feedback contained in the evaluations was only positive and confirmed that the book and the organisation of the research project worked well. The data also contains storytellers' experiences with the process.

The following sections outline the importance of contextual data and how this can influence storytellers' personal development.

5.2.1 Storyteller motivation and emotions in life story work

89% of storytellers said they liked LSW. Several (41%) spontaneously said that they liked it very much. A LSW precondition is that storytellers like to talk about themselves and their life stories. There was no great difference between those who liked to talk about themselves and those who did not before (N:18) and after (N: 14) LSW. Only 6% more storytellers liked to talk about themselves *after* LSW. 50% still did not like doing this. Data confirms that they like to talk most about their past (72% & 100%) and less about their future (65% & 64%) and present lives (56% & 60%). These findings are consistent with the data from the 'LSW experts' (4.2).

67% of storytellers who told stories about their past had photos from their childhood. 79% had photos of biological family members and 84% had other photo albums. This means that about 33% did not have any pictures from their childhood. The meaning for their LSW of this is not clear. They were never asked about it. Some storytellers were demonstrably proud of their pictures. One was so proud of her copied pictures that she decided to give some of them to her siblings. Her interlocutor (I-4/post[24]) said:

> *"She has been so pleased with this. Other people have asked her about it (LSW) and she tells them '...oh...it is so great'."*

56% of storytellers said making the album, drawings, taking pictures and travelling to different places was the most fun.

---

[24] I-4/post means interlocutor (I) number 4 (in the code book), data from the post-interview (post). The finding is marked with 'pre' or 'post' depending on which interview this relates to - but only when it makes a difference.

Others liked to drink coffee and talk with the interlocutor. Two thought ‘everything’ in LSW was fun (N:16). I believe their answers are directly related to their preferences and interests. This is despite some storytellers being challenged by doing things they never had done before.

5.2.2 Storytellers’ experience with the interlocutors and closing parties

Empowerment, including storytellers’ self-determination, is an important aspect of the LSW programme (2.8 & 3.7.1). Their interlocutor was the person closest to them in the LSW process and the person who supported them and observed their feelings of success and self-determination. Their experiences in these areas are therefore included in the analysis of storytellers’ experiences.

Storytellers were asked: ‘what was the best thing about having an interlocutor?’ (N:15). Their answers were that the interlocutor made LSW fun and helped them with practical tasks such as writing. They also said that the interlocutor asked questions that made it easier to remember.

80% of storytellers’ said that they needed help to work with their life stories and that they could not do it alone (see also 6.2.3.3). They said that it was important to sit with the interlocutor alone because the interlocutor then had more time. These findings are mirrored in interlocutors’ experiences (6.2.3.1). Storytellers’ experience of being alone with just one member of staff may help them to discover their own need for intimate conversation. We all open up for a different type of conversation when we are alone with someone.

80% of storytellers also said that the relationship and communication between them and their interlocutor had changed during and continued after LSW (N:15) e.g. S-11 said:

> *Interviewer:* Do you think you and I-11 have good contact?
> *Storyteller:* Yes
> *Interviewer:* Did you have that before you started to work with LSW?
> *Storyteller:* No
> *Interviewer:* So this happened when you did LSW?
> *Storyteller:* Yes, yes (eagerly)

The *closing parties* surprisingly became an important arena for the researcher to observe the relationship, the power balance and cooperation between the interlocutor and the storyteller. These parties were a celebration of LSW (and post- interview) completion. Storytellers, staff and the researcher planned parties together and research funding was used to pay for food.

These parties became, for the storytellers, an exciting and enjoyable end to their LSW. It also gave them the opportunity to show the others what they had made in the LSW. Some of the storytellers, quite surprisingly, took a very passive role. They had been active and proud of their LSW in the post-interview and the audience was made up of people they knew. The party was a surprise after data collection had been completed. It was therefore not possible to explore why some of the storytellers were extremely passive (see also 6.2.3.3).

In one closing party, some storytellers sang a number of songs that they loved. This was a very moving experience for all who were present.

The pictures given below show storytellers' interests, relationships with their interlocutors and interlocutor support.

2

2: Humor and laughter was frequent (PICT0069).

3

3: The storyteller wanted to sing a song that was of particular importance in her life. The interlocutor supported her as she did this (PICT00).

4

4: The storyteller is smiling and telling about her album. The interlocutor is supporting her by asking questions and by taking the story further by reading from the 'sun-model' they have made of the storyteller's interests There is a film clip of this which shows the very positive reaction of the storyteller to the things the interlocutor reads out about her (the storyteller cannot read) (PICT0082).

5: The storyteller was first too shy to tell her stories so the interlocutor started to ask her easy questions and the storyteller got more and more engaged in her own stories (PICT0082).

6: The storyteller asks the day centre manager to read from his album. He cannot read. The manager is sitting below the storyteller. The storyteller appears to be proud. He smiles and shows positive responses when the manager reads (PICT0058).

7: The storyteller has finished presenting his album. The manager touches his arm and says something nice to him. His face is happy and he seems to be proud (PICT0059).

The storytellers were not asked about the meaning to them of the closing parties. The researcher did not think these meetings were more than an opportunity to share the participant's work and to say to each other and to the project 'good bye' and 'thank you'. I however today believe the parties had a greater value to storytellers than this.

Their faces showed expressions of pride. Some were shy, but all told something about their life. They were heard. They had a voice!

The closing parties provided the study with publicity. Journalists in two cities came and wrote an article for the local newspaper. At one location, other professionals and managers from the municipality were invited to attend so they could show them the work of the elderly and their staff and so that they could gain a better understanding of storytellers' lifespan.

5.2.3 The products

Storytellers were proud of their products and had clear ideas about how they wanted to use them e.g. S-18/post[25] :

> *"If someone is coming, I'll tell them to take a look and if I do not know them I tell them 'take a look', because I want to tell them how it was."*

Everyone had something to show at the closing parties. Not all albums were finished. Even so, 17 storytellers had a complete LSW product in the form of an album, PowerPoint presentation or memory-box.

Most of the storytellers wanted to make an album. Some had clear reasons for making what they wanted to make. Others had thoughts about the use of the album, for example:

P-11/WR:

> *"…a time-line related to her life span, because she says her memory is so bad. She wants her past, present and future made into her life-line."*

[25] S-18/post means storyteller (S) number 18 (in the code book), data from the post-interview (post). The finding is marked with 'pre' or 'post' depending on which interview this is - but only when it makes a difference.

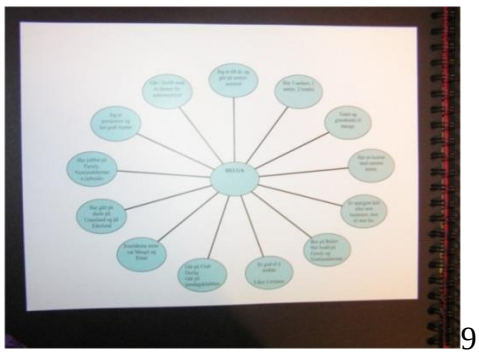
P-12/WR:

> *"…make an album so that S-12 has the possibility to remember/tell about the experiences she has had. Then she can turn the pages in the album and look at all the different stories any time she wants."*

Some wanted to make albums of their own drawings (S-8) or tell stories from travelling or famous people they had met. Most storytellers used lots of pictures in their albums. Others focussed on their stories and used pictures more as symbols. One, who had an interest in computers and photography, made a PowerPoint presentation. None said they were disappointed or dissatisfied with their product. The albums are best illustrated by pictures. The first picture (8) shows an example of an album that can be important if memory starts to fail.

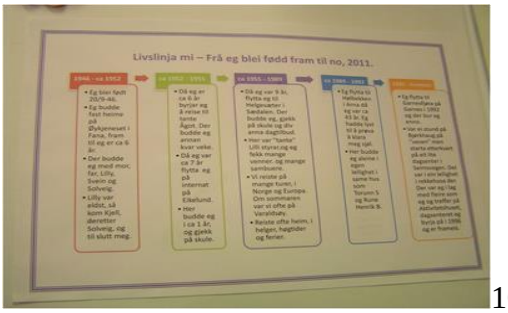
8

8: The headline is: 'Important about me'. Each 'box' contains different topics in her life (PICT0010).



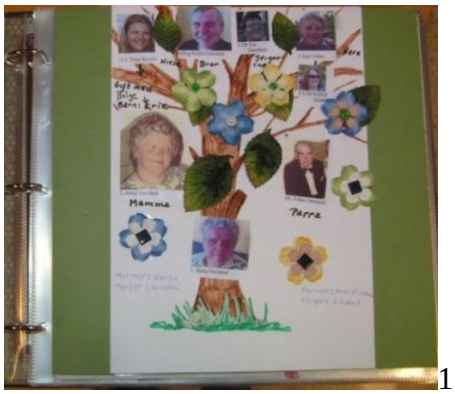
9

*9: The '**Sun-method**' is used to answer the question: 'who am I'. The person's name is in the middle (the sun) and the answers are in key-words around it - like sun rays (PICT0035).*

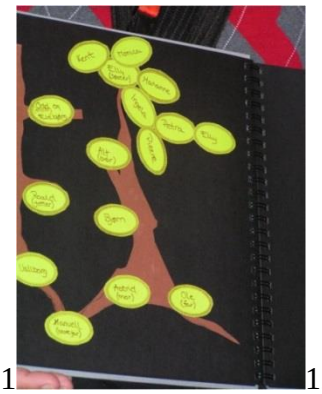


10

*10: A **life line** is divided into different periods, which are described using keywords for important happenings in their life and their age when it happened (PICT0017).*

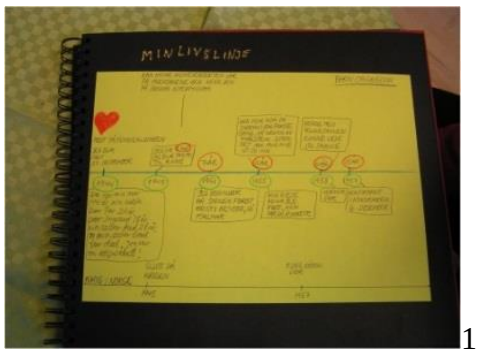


11

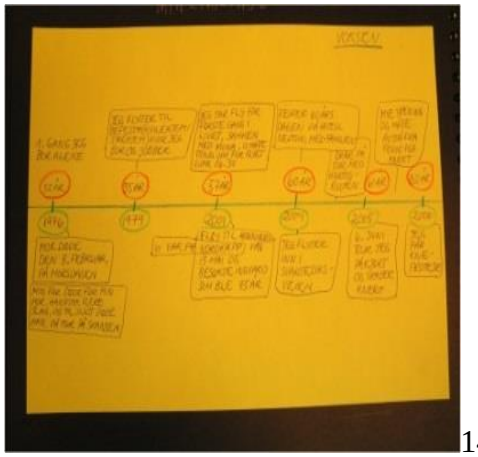


12

*Two different '**family-trees**'. 11: a colourful family tree with names and pictures (PICT00). 12: a tree that uses only text, which makes it easier to see the names (PICT01). This tree has two tree trunks, one for the person's aunt (left) and the other for their core family. This approach is not as useful to storytellers who cannot read.*



13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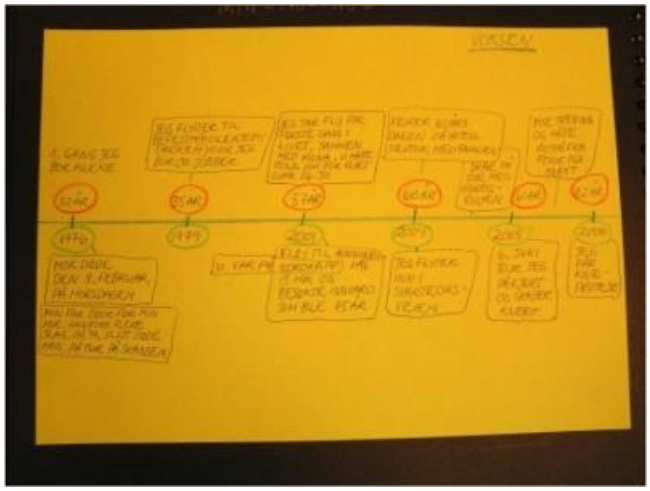
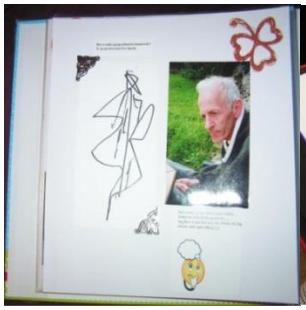
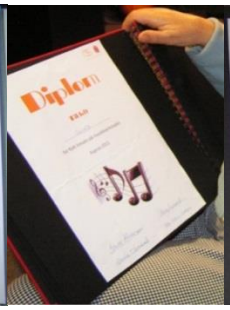

15

13,14&15:
A handwritten life line that shows important happenings from childhood and youth (13), from adulthood; the year, age and happenings the person best remembers (14) as a pensioner and the future (15) e.g. celebration of their 70th birthday. The text in the corner refers to a radio program which the person has listened to every Sunday for 60 years (PICT0005-6-7).


16


17

Albums with decorated pages.16: the album is made of paper-pages in plastic pockets, which makes it easier to revise and also because the album is in a ring binder. The text is handwritten, which may be difficult to read (PICT0105). 17: The text is written on a computer, printed and cut out using special scissors. The album is a spiral binder, which makes it more difficult to remove or change pages (PICT0024).

18 19 20

18: A drawing is glued into the album with a photo alongside of him pensive and text that tells about his interest in drawing (PICT0107). 19: Gluing a diploma into the album from a course provides information to those who read it (PICT0020). 20: Albums can contain a copy of electronic articles on the Internet. This may show something important in a person's life, which other people also know about (PICT0039).


21 22

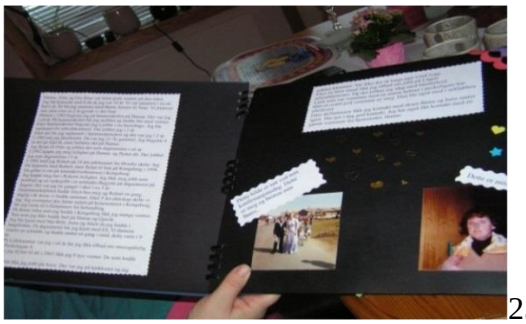
21: Some attached a picture of themselves to the front of the album (PICT0047). 22: An example of a memory box. The storyteller is showing a special item in it. The box contains small albums and things the person can tell a story about. It is easy to replace or add items to this box (PICT0115).

23

23: Text linked to a picture, written on a computer and glued onto décor-paper. The interlocutor told about that the picture and the text ended up being a little skewed in the album and the storyteller saying: "that is okay, because that is how I am" (PICT0004).

24

24: Many pictures on each page in a ring binder with plastic pockets. Left side, in the box; a story about her childhood illustrated by the pictures (PICT0018).



25

25: The storyteller shares an important story which explains some of the troubles she experiences today. The interlocutor first wrote the text on a computer, so changes could be easily made before being glued into the album. The story is decorated with lot of gold hearts that might indicate some of her feelings about the story. There are also pictures of the people that are mentioned in the story (PICT0022).

26

Storytellers showed their albums to other service users, family and staff, S-3 commenting that: "*They are completely overwhelmed.*" Most of them said they felt ownership of their products. It was, however, observed by the researcher that some appeared to be quite detached from their own albums. One example was a storyteller who was asked to show his album to the researcher, who then simply handed it to the researcher. The researcher promptly handed it back and asked him to show it to her, he then quickly skipping through the album. We however talked afterwards about a dog his family had and he remembered exactly where the picture of the dog was in the album. So he maybe was more familiar with the album than the researcher first believed (FR 18-01-12[26]).

5.2.4 Challenges in the life story work process

Some storytellers were sensitive to their inability to do simple practical things. 69% (N:16) of storytellers had no difficulties with LSW. 31% thought it had been hard work and difficult to remember things in their past, e.g. P-13/ WR[27]:

> *"It was a bit difficult because S-13 could not remember when the pictures were taken and where they were taken. S-13 loves to talk about the old days, but she was irritated and said she had a headache when her memory failed her."*

[26] FR: field report and date

[27] P-13/WR, means weekly report(WR) from pair 13(P-13)

Some said writing was difficult and so was finding the right words. It could also become very difficult when the interlocutor had not understood what the storyteller wanted to say. Most storytellers said they received appropriate help from their interlocutor. Some however said that making the album in practice had been difficult.

Succeeding in LSW seemed to mean a lot to them. Not only for themselves. But also because they did not want to 'let down' the interlocutors and the researcher who had shown great interest in their work. This may have put storytellers under a pressure that was not intended. They did not say anything about this. This could, however, have been something they did not want to speak about or did not think about. One storyteller, who was well known for dropping out if anyone placed her under pressure, said she was very satisfied with the LSW. It seems that most storytellers were satisfied with LSW, which the findings reflect.

Analysed phase one data suggested that LSW had an impact on the service user's family and social network (5.4). The focus in phase two was more on how storytellers' social network represented a resource and supported their personal development. I-3 tells about one example of this. I-3 said that it was pity that no other staff had been present during the conversation between S-3 and his brother about 'the old days'. She was sure that S-3 never could have made the album without the help of his brother. I-3 was amazed by the level of contact and understanding between them (FR/I-3).

53% (N:17) of storytellers met their *family* members during their LSW. A comparison of storytellers with parents who were still alive with those with no living family made it clear that storytellers who

had included their family had more family than those who had not included their family in LSW (see table 5.1).

Another storyteller who wanted a picture of her father and her from childhood was sad because her family had told her that she should not contact him. She had lost contact with him early in childhood, but still really wanted these pictures. She contacted her half-siblings, who opened their arms to her. Her father had recently died, so she never met him again. She did, however, get pictures of him from the family.

5.3 Life story work and storytellers' personal life experiences

'LSW expert' statements (4.3) were more or less confirmed in phase two. The main themes of phase two were; the storytellers' personal and identity development and the contextual factors that can support or hinder this. The storytellers' and their interlocutors' were both asked about storytellers' personal development in LSW. Some of this data can be compared, the comparisons being described in this section and chapter six. The following sections outline the influence of this contextual data on storytellers' personal development.

5.3.1 Social network

The 'social network' of older adults with ID is, as mentioned earlier (1.1.1), a special issue. It is also related to their identity and personal development (2.5.2 & 2.5.3). Storytellers in this study were not only asked about the numbers of friends and family they had, but also how often they met, who they liked to be with and why they liked them

best. The distribution of the storytellers' social network is shown in table 5.3.

Table 5.3: Storytellers social network (%)

Social network	**Frequency**
family (N:19)	14 had no parents alive (74) 5 had one or two parents alive 17 had siblings (89) 2 had no siblings
friends (N:17)	8 had one or more friend with an ID (47) 6 lacked friends completely (35) 2 considered staff as friends 1 had family members as a friend no storyteller said they had a boyfriend or a girlfriend
leisure support (N:17)	12 had no leisure support (71) 5 said they did have leisure support

The table confirms studies in this field. Some of the storytellers did have difficulties speaking about this topic. Some of them started to talk about family members that had died with tears in their eyes (S-3). Others recalled how they had been moved away from their friends because of the Responsibility Reform of the 1990s (1.2.1). They talked about how much they missed their friends and how painful it was when their friends died e.g. S-17/pre:

> *"In my last home (an institution) I experienced four people dying in a short space of time, I talked with the doctor about it and now he is also dead…I miss that place and the people so much… my two friends who I had there are now living in S..."*

My impression is that most storytellers missed not having family and best friends around them on a daily basis (see 7.1.3).

31% (N:13) of the storytellers sometimes or often visited other family members such as aunts, cousins, brothers-in-law, children of siblings. 23% were return-visited by the family members they visited. Interviewees sometimes gave surprising answers e.g. S-18/pre:

> *Interviewer:* does your brother visit you?
> *Storyteller:* yes, they are coming next year on my 50th birthday
> *Interviewer:* okay
> *Storyteller:* they have not been here for 8 years and since I moved in here

One person liked to be alone best, and one did not like visitors, S-1 said:

> *"I do not like having visitors, it is better to visit other people. We are so many and I do not have much space, which is why I do not like to have visitors."*

Two persons said, in a weak tone of voice and displaying a kind of shame that they did not know whether they had any friends, while S-1 said:

> *"I do not have one special person as a friend, but that is okay for me. I have my family."*

Some had their best friends in the residence where they lived. They were together every day, playing jazzy and so on. Some had friends they could only meet if staff had time to accompany them there (see also 7.1.3).

Storytellers, after being asking about the qualities of their social network, were then asked the central question of how satisfied they were with it. In both interviews almost everyone (N:17; 88%/N:16; 94%) said they were satisfied with the people they had around them.

One part of a relationship is the interest and feelings people have for each other. The storytellers' answers about who they liked to be with, who they were most fond of and thought loved them most, gave the following distribution;

Table 5.4: Who the storytellers' liked to be together with, were most fond of and thought loved them most (%)

people they really liked to be with (N:15)	*people they were most fond of (N:18)*	*people they thought loved them most (N:19)*
staff 33	staff 33	family: 37
everybody 27	I do not know 22	I do not know: 32
friends with ID 20	friends 17	staff: 16
no-one/I do not know 20	family 17	friends and other people 16
	myself 11	

This table shows that storytellers' were most fond of staff. They, however, believed that their family and not staff loved them most. This is discussed further in 7.1.3. Some of the storytellers did not talk directly about this, the researcher having to find the 'hidden message' in their answers, as with S-5:

> *Interviewer:* Is there something in your life that you are very proud about... that you think you have done very well?
> *Storyteller:* I have it in my album
> *Interviewer:* You have it in your album?
> *Storyteller:* Yes, I have glued in pictures of my sisters and my parents
> *Interviewer:* So you are proud of your family?
> *Storyteller:* Yes

5.3.2 Painful experiences and coping strategies

Storytellers told, in their interviews, about conflicts with neighbours, how difficult this was and how much they appreciated not having to live alone. If they were bored in their own apartment, then it was very easy to visit others. They however also told about how stressful it was when too many people were together in one place. Others had interests that were different to those of their neighbours, which also could be difficult.

Disappointment was another issue. They had been in love, but this had been stopped by service providers and family. They talked about dreams they never believed would come true. One storyteller had, for example, been taking German courses on the radio for more than 12 years. His greatest wish was to go to Germany and speak German. He said*: "I wish I was 30 years old again, I would like to live that time again. The best thing in that time was all the trips"* (S-1/post). Another talked about the assistance equipment she dreamed of getting, but which her key worker always prevented.

Several storytellers were sometimes taciturn about things that happened in the distant past, e.g. P-14/WR:

> *"She does not want to talk much about her life, but I can see it on her body and I can see that it has been bad for her, so she does not want to tell anyone."*

One woman refused to talk about a 30 year period of her life, but talked freely about everything else. Another refused to talk about a twenty year period of her life from when she was about twenty years old, (the quotation is anonymised):

> *"She lived together with both of her parents, but she did not have any work at that time, she didn't do anything. She was not offered work or similar…she received no services in this period; she was at home and helped her parents."*

One story, that represents the institution experiences of a number of storytellers, was told in a conversation between a storyteller and a sibling (the story is anonymised):

> *"… Inger moved from her family home to H. when she was 12 years old, and stayed there until she was 16. Inger repeated several times that "My father carried me through the heavy snow." The rules at the institution were that children could only go home every second Sunday; they should get used to their new home. Both Inger and her brother said that the separation had been hard, because she did not want to live at the institution. About 40 children were living together; boys and girls were separated, but they had their meals together. One of the good experiences at 'H' was a service provider who introduced Inger to singing. She moved with them to another institution and Inger was very fond of her.*

When Inger was 16 years old, she moved to 'V' where she lived for approximately 25 years. She says it was both a good place and a bad place to live…They were six persons in the same room. She did not like this; she has always appreciated privacy. Later on she lived at '2H', in a very small room that originally was meant for the staff. There was barely room for one bed and a wardrobe in it. But it was big enough for her, and it was the first time she had her own key."

Storytellers talked about bullying and about service providers and teachers who had beaten them (see also 6.2.4). One woman talked about a frightening experience during the Second World War, when she lived in an institution. Today she scratches herself when she feels that people are not listening to her, even if she does not want to (S-5)

Some storytellers told that the hard times they had experienced sometimes 'came over them' and that it was sometimes difficult for them to talk about it with other people; 'it is important to keep going and not let bad things take over our lives' they said.

One storyteller told how sad it was that close relatives did not visit her on her birthday. She, however, also spoke about the importance of understanding and forgiveness. Some thought they could manage 'everything', even the hard things. They manage difficult feelings when they are sitting alone and 'thinking about myself,' as told by one storyteller. One said she thought about her behaviour when she was in a bad mood and depressed and tried to find out how to go back to those she had been rude to and explain why she had acted this way.

One storyteller said that she discriminated between her own feelings and the trouble which existed between her parents. She said that when parents were troubled, she had to handle it. This could be difficult as she lacked the knowledge and freedom to act or to move away.

5.3.3 Satisfaction

'LSW experts' said in phase one that LSW makes people more satisfied (4.2-3). The storytellers were in phase two asked about their satisfaction about themselves before and after LSW. They scored their answers by pointing on a table to the five faces (appendix 5), which are defined as: 1: very dissatisfied, 2: dissatisfied, 3: satisfied, 4: very satisfied, 5: super satisfied. There was in general no real difference between storyteller satisfaction with themselves before and after LSW. They were, on average, 'very satisfied (4)' with themselves (before and after LSW); only 12% of the storytellers said they were 'dissatisfied (2)' with themselves before and after LSW (N:17/N:15).

These findings may indicate that questions about levels of satisfaction before and after an intervention may be difficult for people with ID to answer. (Could be difficult for all of us to answer…). 'Satisfaction' maybe is a difficult concept to understand. Storytellers' general 'level' of satisfaction may also play a role. The satisfaction they felt with their LSW was not very different from the level of satisfaction they felt before they began.

79% of storytellers said they love themselves. One storyteller, who was asked about how she had become the lovely person that she really was, said it was the 'staff' that had made her the lovely person she was today. She no longer spoke negatively about herself, which she did before LSW(S-9). This fact was subsequently confirmed by her interlocutor (FR/28-11-11).

Most storytellers said they loved themselves. The storytellers' average ability to appreciate themselves and have strategies to comfort themselves (see also 5.3.6-7) was calculated to be 2.84 points

in the 5 step scale (appendix 5). This means that most were more satisfied than dissatisfied with themselves.

Not everyone had clear answers when asked about the best things about themselves. Some answers were surprising, funny and even sad:

S-9:

Interviewer: What is the best thing about you?
Storyteller: Football
Interviewer: What? (She is an old lady with a walker)
Storyteller: Football
Interviewer: Food bath?
Storyteller: No, shooting the ball into the goal
Interviewer: Football?
Storyteller: Yes
Interviewer: (laughs) what a great answer. So you are the best one at football?
Storyteller: Yes
Interviewer: My God, that was a really funny and great answer - so good. Do you still play football?
Storyteller: (silence)
Interviewer: May be it is difficult now when you are using your walker?
Storyteller: Yes
Interviewer: But you were a great football player before?
Storyteller: Yes

S-12:

Interviewer: What is the best thing about you?
Storyteller: (silence) Oh that was little bit difficult...
Interviewer: Yes I ask you difficult questions…(question repeated)
*Storyteller: (*Silence)
Interviewer: Have you ever thought about it?
Storyteller: No, never
Interviewer: Do you know what you are good at?
Storyteller: I have not heard about that
Interviewer: Do you mean that nobody has told you?
Storyteller: No
Interviewer: I think you are a very good and kind woman, I have not known you for so long time... but I think so. I also think you are a very smiley woman
Storyteller: I can be angry too
Interviewer: But everyone can be that
Storyteller: Yes
Interviewer: And it is good to get it out, we are all allowed to do that
Storyteller: Yes

Both these participants told about their discomfort. S-9 about the ability, the happiness and maybe the status she had as a football player

which she had lost because of ageing. S-12 had never been told what the best thing about her was, maybe because people around her were (in her eyes) more focussed on the things she did wrong than her lovely personality.

A comparative analysis was conducted of pre- and post-interview storyteller satisfaction and various aspects of their lives, both for storytellers and 'their' interlocutors. One trend shown by the data is that storytellers' satisfaction with their past and present life was almost the same before and after LSW. Interlocutors however answered that 24% of storytellers were more satisfied with their present lives after LSW. One interlocutor, I-2 said:

> *"….she is happier and that impacts her relationships with her home staff - she is in another 'cycle', which is more positive and easy…she is more 'upright' in a way, - not physical but in her attitude."*

There was also a trend in the data that relates to storytellers' satisfaction with where they live; before LSW, 48% said they were dissatisfied, while after LSW this fell to 22%. This represents a 26% change in the number who were dissatisfied. This, however, cannot be explained without asking the storytellers.

Few storytellers in this study were dissatisfied with their staff. 79% said staff were 'good and super good' before LSW. This increased after LSW by 5% to 84%. These findings are consistent with how much storytellers appreciated their staff (table 5.4).

5.3.4 The feeling of freedom

The storyteller's answers to the question 'do you feel free to do exactly what you want? was 56% 'yes', 28% 'no'. 6% answered both 'yes and no' and 11% did not know (N:18). Examples of storytellers' answers were (pre-interviews);

S-11:

Storyteller: We can't do everything
Interviewer: No, that is true for all of us
Storyteller: Yes

S-12:

Storyteller: No
Interviewer: What is the reason for that?
Storyteller: (Silence) I haven't wanted to... when you have duties, you have no desire to do the things you not are allowed to do
Interviewer: Okay... so you feel that other people are deciding maybe?
Storyteller: Yes, yes… (eager)

One other question was; 'can you buy whatever you want or do you receive a fixed amount of money to use each week'?[28] 39% answered 'I can buy what I want' and 39% answered 'I have a weekly amount I can use'. 17% had a weekly amount but did not feel free to buy whatever they wanted (N:18). Some examples of the storytellers' answers in the pre-interview were;

S-1b:

"I'm not rich, but I can buy what I need. I don't like going shopping!"

S-14:

Storyteller: I have a weekly amount and because of that I wash my floor
Interviewer: Are you satisfied with that, do you think it is enough money?
Storyteller: Yes, it is enough money

[28] This is a leading question; sometimes the researcher used this approach to give the interviewee a clue based on knowledge of practice.

S-17:

Storyteller: I cannot use more than 800 NOK (about 80 GP)
Interviewer: Are you satisfied with that?
Storyteller: No, would have been nice if it had been more
Interviewer: Is it 800 per week?
Storyteller: Yes, that is little bit too little I think
Interviewer: Okay
Storyteller: When I'm at work I get hungry in the daytime…

When asked how satisfied they were with their opportunities to do things alone, with one member of staff or without the help of staff, 75% of storytellers said they were satisfied. Only 18% of storytellers were dissatisfied with their level of freedom and opportunities to do things alone, with or without a staff member (N:16). Despite this result, some storytellers talked about the limits and roles they live with in their day-to-day lives (pre-interviews);

S-4:

Storyteller: Yes - I have to ask them, the staff
Interviewer: What do you feel about that?
Storyteller: It's okay...
Interviewer: Do you wish you didn't have to ask them?
Storyteller: No, they have told me that I have to ask!
Interviewer: So that is no problem for you?
Storyteller: No

S-12:

Interviewer: What are your opportunities to do things alone?
Storyteller: I cannot go alone because K (key worker) is so afraid that I will hurt myself. I have done that enough and I have been in hospital very often

When the storytellers were asked if they thought staff stopped them doing things they really wanted to do, 43% answered yes, or sometimes, and 28% answered 'no', 28% did not know (N: 14). Some of them said that staff stopped them from visiting siblings, eating food they liked, being together with staff they like (key worker) and some said they were stopped or persuaded from a number of 'daily situations'.

5.3.5 Self-determination

In the pre-interviews (N:18), 61% of the storytellers answered that they in general decided things in their own life, while 17% answered the staff decided things for them. In the post interviews (N:12), 50% answered ‘me’, 25% ‘don't know’ and 17% answered ‘the staff’. The response rate was lower in the post-interview. However, 40% of storytellers gave the same answer as before LSW and the same number in both answered that staff or parents decided in their lives.

The storytellers’ opinion about who decided things in their own home and at the day centre shows that on average 55% thought the staff decided. This was even more pronounced in the answers from day centre users; 72% answered that staff decided at their day centre in the pre-interviews and 62% in the post-interviews (on average 67%). Storytellers often said to the researcher in interviews that the manager decided their lives at the day centre, or their job, for example:

S-12/pre:

Interviewer: Who decides things when you are at the day centre then?
Storyteller: It is one whose name is S... (the manager)
Interviewer: Okay, so she is the boss?
Storyteller: Yes
Interviewer: Who decides things here, in your home?
Storyteller: It is those who are around me
Interviewer: Staff?
Storyteller: Yes

Some storytellers experienced difficulty in trying to decide who they thought decided things, in general, in their life and especially in their own home and at work/day centres:

S-14/post:

Interviewer: Who do you think decides things in your home?
Storyteller: What?
Interviewer: (repeated the question)
Storyteller: Decides?
Interviewer: Yes
Storyteller: (low voice) I decide a little bit myself... No, I don't know
Interviewer: No
Storyteller: (very low voice) it is me that decides…

Interviewer: It is you or the staff or …
Storyteller: Yes, it is the staff
Interviewer: It is the staff
Storyteller: Yes… no…I don't know…

Other storytellers made confident statements about this and were able to discriminate between the past and present when answering 'who decides things in your life?'

S-18/post:

Storyteller: Yes... who has that been then...myself...it was my mother before then, when I lived at home
Interviewer: Yes
Storyteller: It was, yes...
Interviewer: But now it is you?
Storyteller: Now it is me, yes
Interviewer: What is your opinion about the staff in these things?
Storyteller: Yes… they are sometimes... we are sometimes there - that I must decide. They are telling me sometimes, but they mean that I must decide but… they are little bit 'there', but then I get angry... then then....yes...
Interviewer: So you want to decide yourself?
Storyteller: Yes

The LSW programme in this study builds on the 'empowerment-tradition' and requires that storytellers choose their own interlocutors. It was therefore relevant to ask if they had any opportunity to choose their staff in the public services they receive and if this was something they wanted. Only 37% of the storytellers answered this question and the data was therefore omitted from the study. They also answered questions about choosing in their home or day centre. Few storytellers' (12%) said they could choose their own staff all the time and 29% claimed they *sometimes* can chose. 53% experienced that they could not choose their own staff (N:17).

Their interlocutors were asked more or less the same question and data from both groups were compared, see table 6.2.

5.3.6 The feeling of safety and openness to tell and be listened to

About 73% of storytellers said they in general felt safe in their life, while about 20% said they felt unsafe (N:15). About 53% of storytellers felt most safe at home (N:17), 56% of storytellers not feeling unsafe about anything (N:18). Some explained why they felt unsafe, e.g. S-18:

> *Interviewer:* Do you have some bad experiences with darkness or…?
> *Storyteller:* No, not exactly... but I met a man outside when I was 11 years old, who showed me his naked body; after that I have been afraid. I was afraid he could come and take me, I was not afraid before that happened
> *Interviewer:* Was it dark when this happened?
> *Storyteller:* Yes it was 11pm and it was two days before Christmas so I had gifts under my arm which I lost...and I was so afraid, but he did not do anything

Storytellers were asked questions about what they absolutely 'would not dare to do' to explore variations in storytellers' feelings around safety. About 47% said they were not afraid of anything. The variation in their answers did not, however, give much meaning (N:15).

Storytellers were also asked if they feel free to tell staff when they do not agree with them (N:19). Most of them, 74%, said they would dare to tell staff that they did not agree with them. Those who said they did not dare were over 70 years old and did not have a family or a social network; none had living parents or siblings. One had lived for almost 40 years in a central institution and another had remained at home with his mother until she died. None of them could read or write. When they were asked about their feeling of safety they answered 'I do not know' and 'unsafe'.

One issue in feeling safe is that someone is interested in 'you' and listening to your concerns. The table below shows the storytellers,

from their perspective, experiencing much of the lack of 'listening' interlocutors spoke about (6.4.1).

Table 5.5: Do the storytellers experience that staff in their residence or work actually listen to them? (N:11) %

yes, they listen (55), e.g.	no, or only sometimes do they listen (45), e.g.
"I feel they listen well, they have time, - always."	*"sometimes they (the staff) miss things and I get a little bit tired of it sometimes, I do not know if I can do anything about it."*
"if I have something important to say, they do listen to me."	*"I have told her that I want to be with her more, but she does not listen to me"*
	"there are not enough staff, we are six people and only two staff on duty (speaks very intensely about it)"
	(NC/S/pre-post)[29]

Storytellers did understand about lack of resources and talked often about this in interviews (FR). I believe it meant a lot to most storytellers that staff have time to listen to them and to have a conversation without being interrupted. They were, however, very careful about saying anything negative about their staff.

[29] NC: Node Classifications, S:storyteller, pre/post: interviews

5.3.7 Knowledge of their rights, health issues and positive development in old age

Human rights for people with ID is enshrined in the articles of the UNCPRD (UN 2006: see also 2.3.1), which establishes a number of rights for persons with disabilities. Personalised/individual services represent one right users have according to Norwegian law.

You need to know what your rights are to be able to claim your rights. The LSW programme is based on contemporary theories i.e. human rights in relation to a person centred approach (PCA). It was therefore relevant to ask the storytellers what knowledge they had about human rights; if they had heard about human rights and, if they had knowledge about human rights, what it meant in their daily life situation.

Storyteller knowledge of human rights was rather discouraging (N:19) (%):

- 68 did not know what human rights were, had never heard of it
- 21had heard about it, but did not know much about it
- 11answered 'yes' they had knowledge about what it was, but could not say anything more about it

Knowledge about their rights as a service user (N:17) (%):

- 88 did not know anything about their rights as a service user
- 21 answered; 'I know little bit'

These results mean that the concerns in this study relating to ethics and participatory processes are important. They are important in ensuring that the human rights of participants with ID are protected, something which they may not be able to ensure themselves. The findings also indicate the importance of this knowledge in services for people with ID (see 7.1.2).

5.4 Storytellers' personality and identity development

The personal development of older adults with ID, with a special focus on identity development in LSW is, as outlined earlier, a central topic of this study.

It was difficult to obtain from storytellers any clear answers on whether anything in their lives or their thoughts had been changed by LSW. However, 93% of storytellers said they had more knowledge of themselves after LSW (N:15), 7% said they did not. An example is a part of the interview with S-18:

> *Storyteller:* … I-18 said to me 'now I have become closer to you', which is very interesting
> *Interviewer:* Yes
> *Storyteller:* She did not know me... and now we are going to have a map in the office where the things we have written... if new people come they can read it...
> *Interviewer:* Yes
> *Storyteller:* And I say yes to that
> *Interviewer:* Yes, good. But, do you feel that you know yourself better after you made your album?[30]
> *Storyteller:* Yes, yes. I like to talk about my childhood and 'the post childhood' so this was very interesting, really…
> *Interviewer:* Yes
> *Storyteller:* I'm so happy that we started this. I do not regret that I said yes to this.
> *Interviewer:* How nice
> *Storyteller:* Yes, the things you told me about, I have never thought about before

The field reports from the interviews show that the storytellers were in general more relaxed, more open and talkative after LSW, in post-interview.

[30] This is a leading question; sometimes the researcher used this approach to give the interviewee a clue. If it seems that the interviewee answered without thinking about the question, then the researcher used several follow-up questions to clarify whether they meant what they were saying.

They showed a great deal of happiness and pride in what they had made and been a part of. These changes were also observed in those the researcher had known for many years. The observations therefore seem reliable.

The same storyteller (S-18) also told that:

> *"Yes, I have been thinking a lot about the past and if it is right what I have written and said, and everything is right... what I have told so… I have read it through and it is true...I'm surprised about how much I remember…and it is fun looking at yourself, how I have changed…that is really funny... some places I have glasses and other places not... and my nieces and nephews are now so much older, so you see the change, - I am much older now than I was then."*

These storyteller reflections indicate that she sees herself in the 'bigger picture' after LSW, that her life line is clearer to her. This, according to McAdams, is the purpose of life story telling and an important part of identity development (2.6). Storytellers were asked the classical 'who are you?' question about identity, to find out more about their knowledge of their identity.

Their answers were %:

- I am me: 42
- I am… (their name): 32
- I don't know:16
- I have an ID: 5
- Other things about skills or daily life: 5

Storytellers, after a first sentence about who they are, also said:

- Emotions: I'm in a good mood, I'm very happy these days, very satisfied, I have been depressed but now I'm so well and that is so lovely, I feel happy, I like my leisure support
- Things they can: I am a nice boy, I'm actually a well-known person from the football team S…, I'm good at swimming, I'm good at football, I'm good at baking bread, I cycle both ways to my work, I can lift my father up from the floor, I can chop a lot of wood

- Places they have lived or worked: I have lived at Vestlandsheimen (an institution), I have lived for 30 years in F...(a city), I have worked for 20 years at B..(a sheltered workplace), I have been working at S... factory
- Other things: I have the disease diabetes, I took a bath this morning

There were some unexpected answers too, as from S-1:

> *Storyteller:* Do you want me to tell you the true story?
> *Interviewer:* Yes please!
> *Storyteller:* I'm an idiot
> *Interviewer:* Oh, no… do you mean that? But I'll ask you again, who are you?
> *Storyteller:* I'm a great man
> *Interviewer:* Yes, you are a great man S-1
> *Storyteller:* And I like the sunshine, I like going out on trips… I like nature. I like the solid and the usual, I like historical things

Describing your own identity is challenging. It was therefore important to ask storytellers about this from a number of perspectives to find the 'bigger' picture and meaning behind what they said.

The average response rate was 81% to storytellers being asked to choose the following 'best descriptions of themselves' (%):

I am…

- Old (47), young (41); both (12) (N:17)
- Healthy (78), Ill (6); both (17) (N:18)
- Normal (39), abnormal (39), I don't know (22) (N:18)
- Happy (79), sad (11); both (11) (N:19)

I like best…

- Surprises (63), to know what will happen (11); both (21), I don't know (5) (N:19)[31]
- To travel (61), to stay home (17); both (17), I don't know (6) (N:18)
- Be together with other people (61), to be alone (17); both (22) (N:18)
- To sit and relax (42), to do many things every day (21); both (32), I don't know (5) (N:19)[32]

Older adults who feel young in their 'soul' may find it difficult to think about themselves as old. Storytellers answered around 50% young and 50% old as the best descriptions of themselves. This may show that they have a number of perspectives and probably do not lack knowledge on the difference between 'old and young'. The same may be said about 'normal and abnormal'. They also do not appear to make any links between being healthy and 'abnormal'. Many (surprisingly) said they liked surprises, to travel and to relax. They seem to look at themselves and their likes and dislikes in the same way as many older adults without disabilities (see more of the analysis in discussion chapters 7.1.2, 7.1.4 &7.4.1).

[31] In the following categories, the same question is asked in pre- and post-interview. It is checked for reliability and complementarity; if a respondent had not responded in the pre-interview, the answer is in the post-interview and vice versa.

[32] Two questions are omitted from the overview above; 'are you Norwegian or a foreigner' and 'are you female or male'. Everyone answered these correctly, although one person did not know if he was 'a foreigner or Norwegian'.

The interviewees were asked in pre-interviews to choose between the following alternatives to describe why they had become the person they thought they were %:

I'm the person I am because of…

- My job: 77 (N:13)
- My experiences: 75 (N:16)
- My music: 75 (N:16)
- The people who love me: 75 (N:16)
- My family: 67 (N:18)[33]
- My earnings: 67 (N:18)
- The staff: 53 (N:15)
- My schools: 53 (N:17)
- My disability: 47 (N:19)
- My home place: 46 (N:13)

In post-interviews, (no alternatives, N:14);

- Myself: 50
- Family: 21
- Don't know: 14
- Other people: 7
- Learning: 7 (<1)[34]

This may indicate that the most important basis for older adult identity is job, earnings, and themselves as a person. Identity is formed less by family and things they have learned. They also told that music and the people who love them were more important to the formation of their identity than their disability and home. The response rate to home may be influenced by a number having lived in institutions when they were growing up. Staff was one alternative in the first interview. About half told that staff were important to their identity.

[33] There are various numbers of samples in each answer category because the researcher adapted the interview guide to each person and things they had talked about earlier in the interview.

[34] The sum is sometimes 101% or 99% because percentage is rounded to the nearest whole number

None mentioned staff when asked the same question after LSW with no alternatives being given. It is unknown why there is this difference.

Some of the following examples show (post-interview) that asking people about their disability may be challenging:

S-4:

Interviewer: Would you say that you are normal or abnormal
Storyteller: Before 'I started' I got brain bleeding 'here' (pointing at the head)
Interviewer: Okay, so do you feel abnormal or do you feel normal
Storyteller: Normal

S-14:

Interviewer: Have you become who you are because of your family?
Storyteller: Yes, and then I got this damage, yes....
Interviewer: Do you think you have become who you are because of your disability?
Storyteller: (silence) No, I'm not disabled, I'm handicapped
Interviewer: Yes!
Storyteller: No, I don't like the disability... no I'm handicapped, I'm handicapped…
Interviewer: Yes

S-15:

Interviewer: …your disability, does it impact you and your life?
Storyteller: Yes, it has been there since I was a child
Interviewer: Yes, how has this been?
Storyteller: (breathing)
Interviewer: … to have that disability, to have it…hurting you much or…
Storyteller: No, I'm the one I am
Interviewer: Yes, that is true
Storyteller: Y…haa..
Interviewer: And that is good enough
Storyteller: Sure
Interviewer: Yes, so absolutely
Storyteller: My mother, then...she was scared when she was told by the doctor… when I was born
Interviewer: Okay
Storyteller: Because I had this Down syndrome
Interviewer: Yes, so the doctor scared your mother?
Storyteller: He did not mean to, but she had a great shock when she heard that I had Down syndrome
Interviewer: Oh... but then she understood what it was?
Storyteller: Yes, she understood it afterwards...

S-15 shows great insight into her own situation. She also can see her mother's perspective of her disability. Her answer may show that some people with ID are able to share their thoughts and reflect on

their own situation. Their experiences are unique and important to listen to.

One question was about the clothes storytellers' like to wear. Their answers provided no information that could be used to explore the storytellers' identity. This has therefore been omitted. A question that gave more information was 'whether they felt themselves similar or different to other people?' The storytellers' answers were (N:17) (%):

- I don't know: 29
- Yes, I feel similar to other people: 29
- No, I feel different to other people/there is only one of 'me': 29
- I feel both similar and equal to other people: 12

Table 5.6 provides an overview of 'who' they felt similar to.

Table 5.6: Storytellers feelings of being similar to other people (%)

categories	*pre-interview N:19*	*post-interview N:16*	*average: 92*
definitely none	*53*	*44 (<9)*	*49*
family	*42*	*41*[35] *(<1)*	*41*
friends with same syndrome	*5*	*3 (<0.2)*	*4*
Don't know	*0*	*12 (>12)*	*6*
	100	*100*	*100*
		(NC/S/pre- and post)	

The same number answered that they did not know whether they were similar to other people or not as answered that they were similar and answered that they were different. It is worth noting that this was not because they had a disability - but because they felt unique.

[35] One person answered both her family and other persons with the same syndrome.

Few said they were both similar and different to other people, which is a reflexive answer that may be challenging for people with ID. Their feeling of uniqueness recurs when they tell who they feel similar to (table 5.6). Answers that show how unique they feel they are and that they do not feel less valued as a person were surprising. Fewer (8%) felt similar to their family, which may be influenced by 74% having no living parents. This is discussed further in the discussion section.

Storytellers were asked whether they wished they were someone else (N:14). 71% answered 'no', the remainder answered 'yes'. They said the following;

S-18:

Storyteller: That would be fun!
Interviewer: Who would you want to be, if you could be someone else?
Storyteller: No… to be more intelligent and not so stupid in my head - that is not what the name of it is but -I say it like that…

S-15:

Interviewer: Is it sometimes hard to be S-15?
Storyteller: Yes
Interviewer: Is this one reason why you would like to be someone else sometimes?
Storyteller: Yes
Interviewer: If you could change a part of yourself, what would you change then?
Storyteller: Oh my God!

These answers (71%) correlate with satisfaction about themselves and how much they told they love themselves (5.3.3). This data shows a personal strength that may help them overcome what they have experienced and the obstacles they face every day in their life situation.

5.5 Summary

This section outlines the key themes and findings of storyteller experiences with LSW. Important contextual impacts, mechanisms, outcome and phenomena are described.

They are described to show emergent patterns (i.e. themes) through emphasising convergence, divergence, commonality and nuance in the collected experiential data material. Experiences and opinions from individual cases are visualised using quotes. Tables are used to show variations between storytellers and also to provide comparisons of the experiences of storytellers, interlocutors and 'LSW experts'. Most of the findings described in this section are further discussed in chapter seven.

Demographic and contextual storyteller attributions were reviewed in the first section. The samples show a range of gender, cultural background, ages, education and life experience and may be said to be representative of older adults with ID.

The section on the structural and practical conditions of LSW contains data on the issues that are related to the LSW process. Informant experiences show examples of themes that can arise not only in this study, but also in other LSW approaches. The difference between this study and others is the interlocutors' role as supporter and facilitator of storytellers' self-determination/empowerment in this study. A further difference is the valued social role storytellers experience when telling about their LSW in closing parties.

The data in section 5.3 shows emergent patterns arising from the analysis of storytellers' personal life experiences and LSW. Emergent patterns include convergences, divergences, commonalities and nuances that may be related to contextual issues. They may also be related to 'driving mechanisms' behind the evident data on storytellers' change or stability in and after LSW. Storytellers' social network, painful experiences, coping strategies, satisfaction, confidence, self-respect and the feeling of freedom may also influence

their opportunity to achieve self-determination and feel safe. Resolving their lack of knowledge on human rights may be a precondition for self-determination. This topic is, however, not directly related to LSW.

The distinction that is made in section 5.4 between identity and personal development is not necessary. They are, to a great extent, the same issue.

The relationships and weighting between LSW and IP in the PCA were not an issue in data from storytellers. The next chapter is on interlocutors' experience with LSW and is more about the person centred approach and LSW relevance in Norway.

6 The interlocutors' experience with life story work

This section describes emergent patterns, key themes and observations from the interlocutors' experience. The section starts with a section on demographic and contextual data (6.1) and is followed by a section on structural and practical conditions of LSW (6.2), both contextual data and data that may be identified as mechanisms and impacts of LSW. Section 6.3 relates to the impact LSW had on storytellers as observed by interlocutors. It contains findings on personal development in old age, the importance of remembering, the ability to tell and being listened to, storytellers' confidence and self-respect, their freedom to decide and personal and identity development. Section 6.4 is on the changes interlocutors experienced in their attitudes, knowledge and practice in LSW, emphasis being placed on their relationship and communication with storytellers. The next section (6.5) relates to the scope of LSW in Norway and its relevance in today's services for older adults with ID. This includes a section on individual planning (IP). 6.6 is a final summary of these sections. The structural frame of this section illustrates the relationships between the emergent themes in experiences of interlocutors in LSW.

Sources of data in chapter six are post-interviews, pre- and post-interviews with the interlocutors, weekly reports, storytellers' and the researcher's field notes and observations.

6.1 Demographic and contextual data on interlocutors

The interlocutors' answered the pre-questionnaire after they had entered into an agreement with the storyteller to carry out LSW together. Those who dropped out before completing LSW are therefore included in the table below. Unanswered questions are not included.

Table 6.1: The interlocutor's personal attributes and experiences before life story work (N:19) (%)

theme	***characteristics and experience***
sex	17 female (89) 2 male
education/ position/ size	12 assistants/incl. one manager (63) 4 social educators/incl. one manager 3 others with bachelor degree (teacher, child welfare officer, occupational therapist) all employed more than 75%
workplace	11 residential housing (58) 8 senior day centre
number of years knowing the storyteller	8 > 10 years (42) 3 between 5 - 9 years 8 between 2 - 4 years 7.8 years on average: women on average 1.2 years longer (8.1 years) than men (6.9 years)
practical skills as a basis for LSW	1 had done LSW before – but not similar to the LSW in this research 14 had good/fairly good computer skills (74) 5 lacked computer skills

The data from the pre-questionnaire shows that most interlocutors were female, which is common in today's health and social services. Only 39% of the interlocutors had 3 years of higher education or more. This means that there may be a lack of knowledge-based practice in these services.

Most of the service providers are assistants and one of these was a leader. Most interlocutors were employed as staff in the storyteller's home. Day centres were, however, included. This combination is important with respect to the issue of generalisation. One study criterion was that the interlocutors' knew the storytellers well, which the data in the table confirms. Another criterion was that they had not carried out LSW before. Almost none of the interlocutors had heard of LSW before, which lead to them being open and curious about it.

6.2 Structural and practical conditions of life story work

This section outlines the interlocutors' general experiences with the LSW programme and the general structural and critical conditions related to LSW.

6.2.1 Plans and meetings

Some pairs met once a week, others two or three times a week. They were completely free to organise their time as they wished, which was a minimum of two hours a week[36].

95% (N:17) of the pairs made a plan for the LSW work, the pair (P) that dropped out being the only pair that did not make a plan.

[36] An overview of the tasks and stories they reported is given in the weekly reports, with comments and examples from each week, which are omitted.

Only 53% said that their plan was approved by their manager. Most pairs however reported that most managers did everything they could to make the LSW possible.

Some pairs had a clear plan of how they would carry out and complete the LSW. Others did not, as reflected in some of their experiences such as

I-6:

> *"In general, the knowledge I have has taught me to give time, to listen and to know that diversions are not necessarily a change of theme. They will come back again. When I do this again, I have some tricks. Not to be so focused and strict about the topic we have planned to work with, but be more flexible, following the person's thoughts and the process as a whole."*

How much money participants spent on the LSW varied. Some did not spend anything, while one used NOK 900 (about 90 GBP). The 12 pairs who said how much money they used, on average spend NOK 350 (35 GBP) each. 67% spent less than GBP 35 (TN, CN/WR/8b).

14 pairs were able to say how many hours they had used in total on LSW. Three of them had used 8-12 hours, five used 13-17 hours and 18-22 hours, while one pair used 25 hours on the LSW (TN, CN/WR/8c).

10 interlocutors said they spent less than 5 hours on preparation outside of meetings with the storyteller. Two used 5-10 hours and one interlocutor used 15 hours (N: 13). Interlocutors on average spent 4.3 hours on preparation. Some used no time because they did everything with the storyteller (TN/WR/8c). The storyteller had the same interlocutor throughout, a factor that influenced the amount of time used on LSW (TN/WR/8e/N:14).

6.2.2 Motivation

In a hypothetical scale from 0 (not fun) to 10 (very fun), 94% of interlocutors gave a fun score of 8 to 10 (N:17). The result confirms their statement that LSW was 'surprisingly fun, great and exciting', e.g. I-11 said:

> *"We have done new things every day through the process … It has been a fantastic journey, especially because I have known her for so long. The opportunity we have had to talk about memories, good and bad; there is a need to talk about this - really, a big need…I had difficulties to put it out of my mind when my working day was over... I was so engaged."*

Motivating factors interlocutors (N:17) spoke about related to:

- The storytellers' resources, understanding, skills, integrity, happiness and interest; *"S-5 sits waiting for me in the room where we will work before I arrive. That is a new thing! - it pleases me."* (P-5/WR).
- The relationship/cooperation between interlocutors and storytellers; difficult topics were easy to talk about, there were some interesting conversations, a feeling of a safe atmosphere and equality
- Interlocutors gained knowledge about 'themselves' and felt more secure, they learnt to stop and allow the storyteller to come forward, accepting that things happened
- The LSW program; it is a useful and good tool, it was well planned, the weekly reports were useful, the expectations of being a good listener and letting the storyteller talk freely was useful and exciting…'LSW is a survey of psychological needs'
- Colleagues; the interest which the manager and other colleagues showed in the whole process, the encouragement pairs gave to each other by asking 'Have you started? How far have you come?'

We believed that interlocutors' high levels of motivation and the smooth accomplishment of the LSW programme was achieved because they planned LSW with the storyteller. This was not the case, see 6.2.4.It seems that interlocutors' motivation was more due the experiences they had in meetings with storytellers. Interlocutors, in these meetings, discovered new things about the storyteller, about themselves and about LSW that inspired and motivated them maybe also in other areas of their work.

6.2.3 Emotional challenges

Several interlocutors' talked about the storyteller's grief, about the pain of not having children, a husband and a home. Feelings some thought about every day. The interlocutor thought this was one reason for the person's frustration (I-14). They also talked about the grief storytellers still felt many years after they had left an institution, had been abandoned or hurt by close relatives or they had died. For example:

I-3:

> *"He started to talk about his aunt who had told him to use the 'small grey' (brain cells). When he told that she had died, the grief was visual and his tears...That was hard to see. He was so closely related to her, her husband was his leisure support for many years and she died of a heart attack, so it was dramatic."*

I-5:

> *"When they were children they experienced being taken from their families, being sent to institutions and it was not easy to keep contact...so there are many difficult feelings among family members, siblings and parents and it was not easy."*

I-18:

> *"We never talked about it before LSW. She is afraid of her father coming to her house drunk; she got a security alarm fitted because of this. She had a lot of bad experiences because of him."*

Some talked about abuse, others about how they had been strapped and how they had been told to leave a school or move away from a family because of challenging behaviour (the quotation is anonymised):

> *"She told that when she started at school, they threw her out because she could not sit still and after that she did not go to school. Her parents died and she then lived with her brother for a while."*

'LSW experts' told in phase one that listening to others' life stories was a hard and emotional job (4.4). Some interlocutors also told about this in phase two. They said it was hard to listen to stories about abuse or about storytellers being moved away from their home and family and at the same time listen to the storyteller's happiness about small things in life. Some highly sensitive stories were told which had never been told before (the quotation is anonymised):

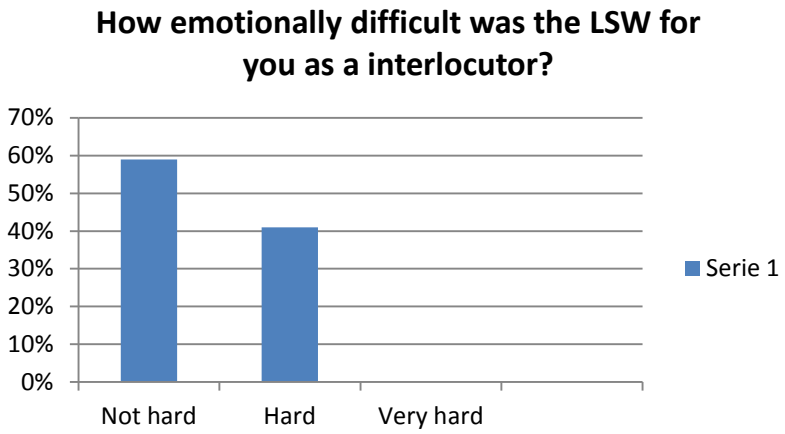
> *"When he talks about this, there is such sorrow in his eyes and even if I have heard it several times, I need time afterwards to be myself again."*

One storyteller told about sexual abuse. The storyteller did not seem to have any trouble with it today. The interlocutor was, however, unsure whether they should report this to other staff because it could become significant when/if the person needed more practical help with personal care.

Some interlocutors said they were afraid of not being good enough at tackling the storytellers' own fear of sharing their stories, especially where they displayed strong emotions. The interlocutors knew of the hard life some of them had experienced and were afraid they would start to cry if the storyteller starting speaking about it.

Despite these examples, in phase two most (59%) interlocutors did not say what the 'LSW experts' had said, that it was emotionally hard to be a listener:

Table 6.2: Emotional burden on interlocutors' when conducting life story work (N:17)



The interlocutors expressed a great degree of proximity and genuine compassion for their storytellers before LSW. Post-interviews confirmed an increased commitment to and deeper emotions for the storyteller. Some of the interlocutors said (first statement is anonymised in the interests of those involved):

> *"She is very dependent on me. Before LSW I felt almost that she struggled against me, but now I see it differently...now I'm thinking 'okay' I will do this, - I'm your best friend. I'm more patient with her now than before. I'm more relaxed now…I was actually sceptical about being in a room alone with her three times a week. But the opposite of what I had expected happened, - and I could not control it."*

I-7:

> *"There is always more than we can see; we are often too quick to draw conclusions (she has tears in her eyes and the interviewer commented on that). I'm so engaged with these people and I do not know where it comes from, the engagement and love has to be there..."*

I-8:

> *"I feel I have great respect for S-8 and I love him so much. When things happen to him, I have to ask myself if I am professional enough, - I have been his service provider for so many years..."*

The interlocutors also talked, after LSW, about the love, patience and forgiveness the storytellers gave back to them, e.g. I-3 said:

> *"I know how important it is to keep appointments and I get tired of repeating 'sorry I can't because I'm sick' – my sickness is not visual, but 'there' you have S-3; he always says 'oh poor you!' When we had our first LSW meeting, the first thing he said to me was: 'Oh I'm so glad to see you again, are you better now?' Several staff in the house think S-3 is very egoistic, but he has so much concern for others. If someone is sick, he asks if they are okay… or 'how are your girls at home - is everything good with them?' - He is so good!"*

6.2.4 Obstacles in the accomplishment of life story work

There was a discussion around whether it was easier to carry out LSW in a day centre than in storyteller's homes. Some argued that it was better to carry out LSW in their homes because staff in these settings had more contact with the service user's family. I-12 said about this discussion:

> *"I think it depends on resources and the people who are doing it. I have also heard this here but I've just done it, despite what other people say. For me the most important thing is to do my job and I really do not know why it should be so difficult…I think it is quite all right to work with LSW in the residence if you really want to get through with it… But we are different persons and so are the service users too, so maybe the approach we used could not be used with everyone in this house."*

Several interlocutors told about absence from work making it difficult to maintain the flow. Only 26% of the pairs reported carrying out the 8 week long process without any interruption. 74% told they had been absent for different reasons (N:19). An overview of the most frequent reasons for interrupting the process were (number one is most frequent);

1. Interlocutor vacation
2. Interlocutor lack of time
3. Interlocutor education/courses
4. Interlocutor sickness
5. Did other things together

6. Storyteller's vacation
7. Not prepared
8. Interlocutor duty hours being changed after LSW began
9. Storyteller was busy with other things
10. A bad period for the storyteller (depression)
11. Practical problems with equipment

Around 35% of interlocutors said staff meetings had resulted in postponed LSW meetings. Interlocutors felt bad and were frustrated when they had to cancel LSW meetings with a storyteller. One storyteller had started to cry when the interlocutor cancelled their meeting. This had surprised the general staff, who had never seen the storyteller like that before (FR 07.03.12).

These findings reflect important concerns in social work in general and are discussed more in chapter 7.2.

Some pairs also said that they had worked overtime to be able to carry out LSW and that it was a challenge when more and more memories came up e.g.

P-3/WR:

> *"… I feel that I have had to make such a fuss to be given time to work on the project and that I have been lagging behind with my other work…I know it should not be like this, but theory and practice is not always easy to combine, as 'I want, I want, but I can't."*

A very few interlocutors experienced negative reactions from colleagues e.g. I-12 said:

> *"There was one day when a person was negative towards me, - that I used time on things like this. I don't know if it was a kind of envy or what it was, but I didn't bother about it. Our manager is very positive to it, so... that is the most important."*

6.2.5 Relational issues in life story work

Some interlocutors said they did not contact the storyteller's family in LSW because the storyteller did not want to include family members. Others thought it was more important that the storyteller told their story only from their perspective, e.g. I-12/post said:

> *"Her understanding of her life story is different to her parents."*

One interlocutor experienced a dilemma because they had received information from the family which the storyteller did not know about. The family wanted this kept secret. Meetings with family members had also been challenging because during the meeting;

- They talked about the storyteller in third person and understatement
- They talked about painful events which the storyteller explicitly had said they should not talk about

One manager said that a sibling of one of the storytellers had not wanted her to participate in LSW. The storyteller however really wanted to participate and had the authority to decide herself whether to participate. The staff agreed with the service user, who had a great time as a storyteller.

In one of the closing parties a storyteller said they wanted to tell a very private story. The manager told the interlocutor to persuade the storyteller not to tell it. The interlocutor felt bad about this afterwards even though they thought it was best for the storyteller. A similar situation occurred when a storyteller wanted an interlocutor to write in the album about a person that had been hurtful to them. The interlocutor dissuaded the storyteller from this.

6.2.6 Storytellers' passivity and interlocutors' trust in the story told

Sometimes the storyteller's *passivity* and their lack of any verbal language to tell a whole story was an issue the interlocutors thought was challenging. This includes where it was discovered that the storyteller had hearing and visual problems. Some comments from interlocutors about how they felt about a storyteller's passivity include:

I-3/pre:

> *"I relate this (his passivity) to his personality, S-3 gives little under his own initiative, so it is more about putting him on the right track - then he does respond… if he wants... he does not do anything independently… so everything depends on me." (I-*3/pre)

I-9/pre:

> *"She does not take the initiative, she never does, - and it is always me that has to* ask."

I-9/post:

> *"I have learned that you do not get anything out of S-9 without 'dragging it out' of her, and it has been a job, really... she was not very interested in talking, but she wanted to go in there (the room they used for LSW), she was very clear about that."*

Some interlocutors observed how challenging it was for some storytellers to concentrate. Some interlocutors also had concerns about the accuracy of the storytellers' memories. Did they really remember these stories from their past well enough to tell them? Some interlocutors questioned whether the stories were true.

Some pairs reported that it was difficult to follow one story and not mix it up with other stories. Others said it was easy to find stories, but difficult to choose which stories to include in the albums. Some interlocutors were frustrated because the storytellers avoided describing their feelings in stories about difficult events.

6.3 Interlocutors' experience with storytellers' personal development

This section outlines the importance of interlocutors' experiences with storytellers' LSW, especially their personal and identity development.

6.3.1 Positive and negative development in old age

Positive development includes a feeling that 'life is going forwards' and not 'backwards'. Interlocutors were asked to define positive and negative development for older adults with an ID. All had different answers (which was to be expected).

A considerable amount of data was collected about issues related to positive and negative development in older age for service users with ID. Most of the analysed data relating to this topic has been omitted as the maximum thesis length would have been exceeded. Some extracts are given below:

> *"Positive development in older age means that the service users feel they have a good place to live and that they feel safe about where they live.*
>
> *The focus of staff must not only be on health issues and leisure activities. Good social networks are also important.*
>
> *A positive life is when people can be active and have variation in their life, which makes it interesting to live.*
>
> *They should have opportunities to learn new things and get feedback on things they are good at, it is also important that they feel connected and linked to the people around them.*
>
> *It is important to have fun, to enjoy and decide things - and be respected for the choices they make.*
>
> *Positive development means to have knowledge about themselves, and to be able to decide about the involvement of other people in their lives, to feel free to 'say things' and to speak without interruption.*

They should be helped to adapt themselves to the ageing process, the changes that occur and for them to feel comfortable with these changes. They must be allowed to be old and to say they are not interested and to be themselves 'then and there'.

They should be respected for the person they are and feel valued.

When skills decline and they do not understand why this happens; staff must explain to them why this happens and help them, in a respectful way, so they feel they can manage the situation.

Staff should also help them reach their life goals and desires. Staff must respect their individuality and that some become older before others - that everyone has their own pace.

Positive reactions from staff, good attitudes and love from the staff are very important (NT/36-36b)."

These extracts from interlocutors' descriptions of positive development in old age says something about knowing that people need to take care of themselves and make good decisions about their life. But most of all they describe important issues that are related to their own attitudes, knowledge and practice. Interlocutors also told about more fundamental issues and LSW, such as believing that people carry on developing for as long as they live. Others include:

I-5:

"They are not different from other elderly, we also want to talk about our life and the importance of it -it is the same for them."

I-14:

"For me it is a new way of thinking, that they are going to develop when they are older too... but one is never too old for new knowledge and this is another way of looking at life. It was, before, more common to think that ageing is just the downhill slope after you have climbed to the top in your younger days – this kind of thinking is now 'out' …There are no differences between people with ID and other elderly when it comes to development; it is only on another level. They can also learn to use a computer, even if they do not learn it in the same way as a person that has been a professor."

I-15:

"Observing S-15 in LSW, I see the possibilities for development and development in so many things. I have been thinking that they might not develop so much, it is more stagnation, but I see now there are many things they can develop."

Some interlocutors thought LSW was the answer to helping older adults with an ID to develop their lives in a positive way e.g.

I-5:

> *"…I think that it is development… to work with their stories - they experience development through their stories by talking about them."*

I-17:

> *"He has got a better knowledge of himself. That he can share with someone, that he has a story to tell about his life that makes him grow. He grows when he talks about it."*

6.3.2 The importance of telling and being supported to remember private stories

Both the storyteller and interlocutor were always positive when asked to say something in their weekly reports about 'how it was to tell and to listen'. One pair said (P-3/WR):

> *"I have personally never experienced such long conversations with S-3, and I have never seen other people in that situation either. What made this so exceptional was that he was so keen to share this part of his history with us. He was not focused on the nice shower and fantastic lunch that day – it was all about his memories from the past."*

Several interlocutors, mirroring that said by the experts in phase one, in phase two told stories about LSW 'opening up the door of people's history' and emphasised the importance of finding the service user's 'lack of life story' and helping them to remember e.g. I-11;

> *"Before S-11 remembered everything in her life so clearly, but in the last few years she began to have trouble putting her memories together in the right time order. When she got the book finished, she ran around here and showed it to everyone. The book helped her to put all her memories in chronological order... it was fascinating to see how clearly she told her story when she used the book...she remembers everything now, when she is looking at the book."*

I-2 said she learned more about things that had been difficult for S-2. She had discovered that S-2 actually remembered a lot of things, more than both and the stories had become longer.

They had known each other from 1987. Despite this, there had been a change between them. I-2 said:

> *"There is a change because when we talk about things now … I may say 'do you remember you told me...- and she says: 'oh, yeh it comes to me little by little' … I give her some small keywords, but not as many keywords as before. Yes, sure... I do have more time to listen to her now and when she talks I think about what she is telling me…"*

One remarked that service users are used to 'waiting and waiting and waiting'. The biggest change LSW represented was that they were asked to tell and not to wait. Others said it was easier for staff to ignore people with 'mild to moderate ID' than those who needed more help because (I-4):

> *"They are starved of others listening to them and giving them attention… S-4 is not saying as often as before "nobody is listening to me!" or "nobody has time to listen to what I'm going to tell!"*

The interlocutors said that storytellers felt more important than before because people were listening to their stories. Which led to new stories. The interlocutor thought it was therefore important to listen every time:

I-2:

> *"I think she looks at herself as more important than before, I think she feels that people are listening more to what she says…I have changed too."*

I-9:

> *"Previously people did not have time to listen to them, so to get them feeling...that people are interested in their life and listening to them, - must be very positive."*

Interlocutors often had the impression that storytellers had a lot of things 'trapped inside'. When they were given the opportunity to tell about painful experiences, about things they had never spoken about before, then they also were also given the opportunity to work it out themselves. Interlocutors reported on storytellers who did not want to tell about painful things.

The interlocutors however thought that if staff knew about these things, then they could help them and possibly avoid more pain. It was also easier to talk about difficult things when they were doing practical things together i.e. making the album.

Several interlocutors observed their storytellers had a need to talk more about certain periods of their life and to find answers. Some managers did not support contacting a professional about this.

Interlocutors changed their view of stories which some storytellers had been telling for many years. They had carefully listened to these stories for the first time in LSW and had understood the importance of them. This change of view was something they wanted to take with them into future work. They looked at this change in themselves as a positive for all service users.

Interlocutors said that storytellers repeated some of the difficult stories and spoke about how hard it was to listen to them. They also spoke about how they opened up to storytellers so that they would feel safe when talking about difficult things, e.g. I-7:

> *"I know that she has had a hard life... but she did not show any reaction before the final day, when I saw tears in her eyes and when she looked at me and I did like this with my finger (as if she was crying). She talked about it afterwards... for the first time she talked about her feelings. She wanted to say that she had cried too."*

6.3.3 The importance of storytellers' confidence and self-respect

The interlocutors reported that a routine of regular meetings of fixed length opened up the storyteller and helped them feel a trust and confidence in themselves and their 'hidden' abilities.

Storytellers took over more ownership through the LSW process and some interlocutors experienced a totally new situation with them; they developed their relationship and felt safer with each other. One example from I-2a is:

> *"… she is more patient and has become more tolerant. One person she often argues with is S-1 and I can't remember if they have been arguing at all since we started. Maybe they feel more equal now, because both of them are doing the same thing - LSW. She does not show as much challenging behaviour as before; I don't know if this has anything to do with LSW or something else."*

It is great if LSW can prevent challenging behaviour, as I-2 states. This means that there are 'mechanisms' in the LSW programme that support storytellers in managing their life in a better way.

Storytellers also became more open and comfortable as the pairs got to know each other better than they had done before. The feeling of confidentiality may also be expressed in the way the storytellers' communicate, how openly and freely they communicate things in social settings. In post-interviews, interlocutors were asked if they had observed any changes in the storytellers' communication. 77% said the storyteller had changed the way they communicated (they were now more talkative and took more initiative), while 23% of interlocutors had not observed any changes in the storyteller's communication. 64% of interlocutors said the storyteller talked about other things after LSW, while 36% did not think this was the case (N:14). Examples from interlocutors include:

I-2a:

> *"I see that S-2 feels more secure now, and she does not say 'I do not know' so often. She seems clearer about what she wants to say; she seems more secure about what she shares when more people are together - I can see it in the group. She seems to have become more self-confident. "*

FR: I-11:

> *"I-7 felt she had more contact with S-7 after LSW and that S-7 stood out more distinctly in the milieu."*

I-18:

"She is more secure now (after LSW), she has told me that. She feels she is closer to me now".

I-15:

"Yes. When S-15 has a good day, then we have good conversations. I notice that S-15 is older now and some things which she easily understood before I am now not so sure about, so I have to make sure she does understand and then she might feel safe."

The answers of interlocutors who were asked about 'their' storyteller's confidence and self-respect (before and after LSW) were a little different from the storyteller's answers[37] (appendix 5). 41% of interlocutors' did not observe any changes in the storytellers' confidence. This is greater than the 30% who observed a change or the 29% who thought the storyteller was not as confident as at first.

Interlocutors assessed the storyteller's confidence to be 3.37 points before LSW and 3.64 points after LSW. This means that storytellers had confidence and self-respect before LSW and that the interlocutors assessed this to be close to very confident/very great self- respect after LSW. The best result would have been where all had changed to 'very confident, with very great self-respect'. We should, however, bear in mind the harsh life most of them have lived and the influences of environments. The results are, based on this, good, even if they could be influenced by the interlocutors' increased knowledge of the storyteller's personality.

[37] The table in appendix 5 was interpreted as: 1: very uncertain /very little self-respect, 2: uncertain/lack of self-respect, 3: confident/self-respect, 4: very confident/very great self- respect, 5: super confident/ self-respect is high as it can go

The interlocutors' assessment of storytellers' self-respect was that it was more or less the same after LSW as it was before. But there were variations. Some assessed 'their' storyteller's self-respect to be two points less after LSW than before. This difference may be explained by the interlocutor's deeper knowledge of the storyteller's life and not that the storyteller had less self-respect after LSW.

Interlocutors that gave storytellers the same confidence and self-respect scores before and after LSW may have known them well before LSW.

Some interlocutors said that LSW gave the service user a more serious role. I-6 said:

> *"…having an overview of their lifespan may have a great effect, they may experience greater value and status...they have more value."*

This correlates with results from a question on how useful storytellers feel they are. Around 82% of storytellers found that other people asked them for help and they felt they were 'a helpful person'.

There was no clear difference in storytellers' satisfaction with their health after LSW. Interlocutors thought there would be fewer mental problems if people were more open about their life stories. Every (100%) interlocutor (N:16) said, after LSW, that they thought it would mitigate psychiatric problems and that LSW was especially useful for people with dementia. I-9/post said:

> *"... to look at herself in a positive way, - is a good thing for her in building her psychiatric health... also that she feels proud and that she is a part of something."*

6.3.4 The storytellers freedom to decide

A storyteller's lack of freedom to do the things they like to do and their self-determination was more strongly expressed by the interlocutors than the storyteller themselves. Some interlocutors said that (post-interviews):

I-3:

> *Interlocutor:* …you may facilitate self-determination in a way so he believes he has made a decision himself, I cannot answer for what all other staff do. His capacity regarding self-determination is unfortunately undermined, even if you want him to decide... if he could have decided... he would have taken a shower and a bath every day, but that... is not possible. He does decide for himself when he is out shopping, for his food and so on, but his clothes is decided together with the staff... so he decides a lot of things but it does depend on having staff support, how many of us are at work...It depends on the staff available and the situation, he may answer 'yes' to everything the staff say, most of us do this in our work, we ask in a way that means they cannot say 'no'... I call it 'voluntary compulsion'…. They are so isolated, the only social meetings they have with others today is CD which is once a month, except for national holidays.
>
> *Interviewer:* Is that the only leisure activity he has?
>
> *Interlocutor:* He has that and once a week he meets with a group of five others. But this is not working very well because they are five persons with very different needs and only two staff. During the whole summer there has not been any meeting because one of the staff was sick and the local authority did not replace her. There is also something we call a 'song-hour' here at this house. That is also very good for S-3, with one of the staff playing guitar. When it is possible, we try to take him and the other resident with us to the church on Sundays. He loves that because he knows all the songs
>
> *Interviewer:* So even then, he is dependent on others?
>
> *Interlocutor:* Yes, but there are eleven people in this house and if only three of them want to go, we cancel it

I-12:

> *"It is us, staff who decide; if we say no, nothing happens. Then they don't get to go on holiday and they are left in their apartments, unless their family takes care of them*."

I-13:

> *"We have a rule here in this house that if they are going to... if they are going to have soda water, sweets and things like that, they have to eat it in their own apartment. But if they share it with others, they can sit in the common room."*

Interlocutors thought storytellers had many self-determination opportunities, despite some interlocutors' statements indicating a lack of this. Only 16% in the pre-interview said storytellers had few opportunities to decide important things in their lives. In the post-interviews, a further 16% claimed storytellers had plenty of opportunities to exercise self-determination, even if some still denied this.

The LSW programme in this study builds on the 'empowerment-tradition' and requires that storytellers choose their own interlocutors. It was therefore relevant to ask if they had any opportunity to choose their staff in the public services they receive and if this was something they wanted (see 5.3.5). Their interlocutors were asked more or less the same question by answering a statement; 'should users decide who they are helped by'.

Table 6.3: Interlocutors' opinion about whether service users should decide which service providers they are helped by (%)

storytellers' experience, N:17 (from 5.3.5)	*interlocutors opinion, N:19*
no 53	16 not agree
sometimes 29	47 partly agree
yes 12	37 agree
Don't know 6	
	(NC/S/I/pre- and post)

63% of interlocutors' answered that service users should only have a partial or no opportunity to choose their own staff. The arguments they presented for not letting storytellers chose their own staff were as follows:

- ✓ The way the service is organised today makes this impossible
- ✓ Some of the staff will be popular, others not and that may depend on how permissive some of us are

- ✓ Users may cause stress upon staff who know they are not wanted
- ✓ Some users may become dependent on certain staff, which can then prevent the user doing things in their daily life (because they are waiting until that particular staff member is on duty)
- ✓ What if 'their chosen' staff member stops working at the centre? Would it not upset the service user (and cause them to grieve over this?) Therefore, because of this, it is beneficial for the users to get help from a range of different people, - but not from too many people
- ✓ Staff have to treat everyone equally and because of this and practical conditions, it is not possible to let people choose their support staff
- ✓ The same applies to the staff in reverse, we cannot choose who we work with and we have to help the person who needs help…

Other interlocutors' were more positive about letting service users choose their support staff e.g.:

I-1:

"It has something to do with respect and humility for the situation, and we must respect that we are going over their doorstep and into their home."

I-6:

"If I was in that situation, I would want to decide this… it should be a human right!"

I-18:

"…all their life they have been in a situation where they have received services. At least in old age they should have a team around them of 'their' chosen staff - depending on what they wanted to do…I'm a tool or an aid for her to meet her desires, needs; ideas...yes…"

Interlocutors were asked if they had observed any changes in their storyteller's empowerment after LSW. Only 58% of the sample answered this question, which is too few to indicate a trend. They provided more information in the examples they gave and in

conversations we had on this topic than in the formally quantified data. Some interlocutors talked about the small steps they had taken and how the storyteller had become more and more active and clearly believed more and more in their own ability to do things during LSW. They talked about how the storyteller had been afraid to write in the album at the start, how they had changed over time and how proud they were now about it. For example:

I-2:

> *"It was difficult in the beginning not to manage the situation, but I let go of my control and let S-2 take control. It was exciting; also because I know S-2 very well, I am so involved and I am an important part of her life stories."*

I-4:

> *"I have tried to influence her choices and maybe I should not have done that, but then she has been very clear about saying 'no'. I asked her if we could call her sister and ask her about something, but she said 'no'... a very clear 'no'. Well, well I thought then, we can wait and take it up again after some weeks... but when I asked her again, she said 'no' very clearly again. She wanted only herself … and I think for her... this (LSW) should only be about her. She did not want anybody else to get involved. It should only be me and her….I now have more insight into her life and I see that she does have a strong will - I did not know this earlier because she always said 'yes' to all my suggestions... she was so clear when we did the LSW and I admire her for that, I think she is tough."*

I-9:

> *"I have seen a huge difference in her…. she was clear about what pictures she wanted to put into her album and which she didn't. My suggestions did not help and that was quite okay for me. It is exciting that she has such a clear view of what she wants. She doesn't even say things just to be polite…that is actually good, because it shows that it is her who decides, and that is good."*

It was interesting, in the light of how interlocutors and storytellers cooperated in this study and LSW, to hear that some interlocutors explained the lack of self-determination as being due to the storyteller's abilities or lack of staff:

I-1:

> *"S-1 has clear wishes about what he wants to do, but he is not able to do it because of the help he needs…they cannot go to the things they want to go to because they lack staff in his home, so that is very sad. Last year the 'summer trip' was cancelled because there was a*

discussion about salary and regulations when we (the staff) are with 'our' service users on trips, so everything was stopped."

I-4:

"Even though she has not lived in an institution for a long time, she still thinks that the staff decide things in her life."

I-5:

"It is difficult for her to decide things and even to have the chance to decide things. I think it is more likely that other people decide instead of her. She does not have the ability to influence decisions… You may see from their body language that they not are used to deciding things."

I-18:

"…we have a lot of power over them. That is bad; they do not even decide about a trip to the cinema without asking us. It is their life and they are adults, so it is bad that they have to ask about everything, - even to have a sandwich. And we make it worse for them by saying to them 'oh – go and ask your key worker."

6.3.5 Storytellers personal development

It was important that interlocutors understood the concepts used in the questions they asked. They were therefore asked about what they understood about, for example, 'personal development in general'. They had a number of opinions about this and some of them thought, even though 'personal development' is a common term in literature and in the media, it was a difficult question. I-8/pre, said it was:

"…difficult to answer this, because we are all the time talking about protecting what they stand for and manage, and now you are talking about development...(laughing), it is difficult..."

Most of the interlocutors' answers were considered by the researcher to be relevant. It was, however, difficult to extract clear results from the data. The data was therefore omitted. The interlocutors had, however, some noteworthy reflections. For example, I-15/pre had reflected upon the difference between personal development when people with an ID are young as oppose to when they are older:

"I observe that her attitudes are more constant, in her opinion of the world and that she may have been at her 'peak' of personal development... but that is not negative because she is now older and may have a different rate of development than when she was younger, maybe it's like this for all of us - because we are all different persons.

She still develops because she is open to the world and when we treat her with respect and openness, she may even achieve greater personal development".

63% of interlocutors said in their pre-interviews that they believed the storyteller they supported was capable of greater 'personal development' (N:19), only 10.5% believed that their storyteller was not able to achieve this.

When they asked whether they believed storytellers had an equal opportunity in 'personal development' compared to people without ID (N:14); 29% answered 'yes', while 71% believed 'to some extent yes' or that they did not have the same opportunity as others. Despite this, 71% of interlocutors said, after LSW, that the storyteller had changed and 'developed personally'. Some of these quotes are reproduced below. These quotes also show what some interlocutors defined as personal development among storytellers:

I-4:

"Even if she does not want to talk about everything and 'periods' in her life, I think she is more aware of them now."

I-6:

"Her 'solo' behaviour has been less prominent; she gives more 'space' to her two siblings now and she reflects more - that she is an adult."

I-7:

"In the beginning she did not want to write in the album, but after a while she did."

I-11:

"She is a self-confident person, and even more so now I think."

I-12:

"She takes greater initiative. Previously she said 'yes' or 'no' and accepted the things we told her, now she is asking, e.g. 'when are we going to make the next story?' She also suggests new things, and I like that, it makes it more interesting and fun."

I-14:

"I see that she has the potential for development, which I was not aware of before… In our last meetings she was more patient when working with her stories."

I-17:

"He is clearer and stronger in his opinions.

Some quotes in weekly reports which the pairs wrote together were:

> *"From the perspective of S-6… her experience is that she is important, that the story of her life is valuable to me and to others. It gives her more self-esteem and makes her feel as if she has more integrity."*

> *"S-7 thinks we have got to know each other better and that she has got to know herself better."*

After LSW, more interlocutors said they thought LSW could help the storyteller to achieve personal development, e.g.

I-4:

> *"LSW encourages her to continue to be as open as she is now. She has been that before too, but much more now. I have to think more about her past and help her to tell the great stories she is able to tell from that time."*

I-5:

> *"I think this (LSW) is very important for personal development. Yes... the process does something with us... it is a huge task to go back. Sometimes we see fast and very positive reactions about things we thought were just minor to them. I think this is because they are not used to be respected and to be talked to in a respectful way."*

I-7:

> *"She is talking louder now... She is getting more attention from others now, by saying louder 'look here what I'm doing'."*

I-11:

> *"…to work the way we have done in LSW is a great process, it lifts people up."*

I-15:

> *"…before she was not strong enough to stand up for herself. I don't say that everything is okay now, but it is better. We have found a good way to do this, and I feel she manages to get involved 'in it' much more now than before."*

Some interlocutors were negative about encouraging storytellers to think about personal development - they were not sure if it was possible:

I-16/pre:

> *"Development...yes... it may be that we have a potential to develop when we are old, but I don't know... with help I think, - but in general...I think if she is to change or develop, she needs help to manage some of the problems that are fundamental for her, now she is almost 50 years old and it has not happened so far, so maybe she needs some treatment or...some help to manage her difficulties?"*

I-1/post:

> *"I'm not sure if this can stimulate him to personal development, but he will be satisfied when he gets the opportunity to go back in time and travel to various places. Maybe he remembers things when he is there. He will be happy about it, and that is the best thing with this (LSW)."*

Other interlocutors admitted their own limitations about encouraging the storytellers to develop themselves, for example I-14:

> *"I see that one of my weaknesses is that I give up too fast...because I have been afraid of pushing. I see now that I don't need to push, I just have to find the right way or 'door'."*

Interlocutors' experiences with storytellers' personal development is exciting, especially considering that this was not a topic they had thought about before. They discovered the person 'behind' a service user and they recognised the potential each storyteller had to take responsibility for their own lives and that they had the ability to grow personally, in their own way. I believe that the experiences of interlocutors with their storytellers impacted their attitudes, knowledge and practice (6.4). This 'Person centred Learning Cycle' is discussed further in 7.2.

6.3.5.1 Identity, in particular

Interlocutors thought LSW helped storytellers to gain an impression of 'who they are' and that this was particularly important. They recognised a storyteller's identity development was influenced by telling others about their life story. Their self-esteem was particularly influenced when making an album about their lives. When they said 'this is my desire' or 'this is a book from my heart', it meant something of great important to that person, e.g. I-2 said:

> *"It has something to do with their identity where they are allowed to say 'this is my story', 'these things happened to me', 'it is my experience', - and no one else can say 'no, this is wrong!' It is our responsibility to strengthen them by saying 'this is your story and no one else can tell you that your story is wrong'."*

The interlocutors were asked how they would describe a person with a strong and positive identity, to obtain a more nuanced picture of what those close to storytellers understood with the 'identity concept'. They had a number of opinions about this and some of them thought it was a difficult question:

I-14:

"To have an impression of who you are is so important. It is more important to have a clear feeling of identity than to have self-confidence, it is underestimated."

I-19:

"A confident identity and a confident personality is the same."

When the interlocutors were asked if 'their' storyteller had a strong and clear identity, they answered (pre-interview/N:19) (%);

- Yes: 58
- Partly: 32
- No: 11 (>1)

Some examples of why they thought storytellers had a confident identity are:

I-1:

"I think it is because he has lived at home with his mother until adulthood. He has never lived in an institution and he has always had good contact with his siblings. He has a big family and is fully included in everything that happens."

I-16:

"There can be several reasons for this; maybe they have got a little bit strength from where they live, - we are very focused on that 'here'. They are allowed to speak out and they are allowed to be angry when there is a reason for that… they are allowed to cry … when something is sad and they are allowed to say 'I don't like you'… it is also about the environment; 'here' we want people to speak out - and this.. I tell them this as often as I can."

After the LSW the interlocutors were asked if they had observed any change in storytellers' identity and they said (N:16) (%);

- Their identity strength has changed/increased: 69
- Their identity is the same as before: 25
- Not sure if they have changed or not: 6

Some changes the interlocutors spoke about in the post-interviews were:

I-4:

"…I think a process has started even if she does not want to share that with everyone - I don't think she wants that."

I-5:

"... the importance of this is so... they say that people with ID have a cognitive decline... but she is so good... she has grown... she feels more important now... I think she has another position in the group now, more 'here I am'…I think she feels more important and has a stronger ego now."

I-7:

"She has been more talkative in the common room. Maybe that is because I see her more, and she gives more physical contact... not only to me... On one occasion she said in a loud voice 'look here'...and then she showed the knitting and the colour she used; I have been thinking that... that is a change."

I-8:

"… after we have been on a trip to places he had lived before, he talked about it at home and after meeting the family; he smiled all time when we said to him ' I've never heard this before'. He was so proud and said 'did you hear it, did you hear it...' - so yes, he has increased his feeling of identity because someone listens to 'his life'. He is not able to tell this with his own words."

I-9:

"…she has a slightly better self-image, - something has happened to her... people 'here' are talking about their LSW and then she says that she does it too. That gives a good feeling and the result is better self-confidence and self-image…Before she always said: no I'm not pretty, I'm not good! When I said to her 'you are great' she answered 'I'm not'. In the first two meetings, when we were looking at pictures, she said this to me. But afterwards, in all the other meetings, when I told her how pretty she was in the pictures, she did not answer as before. Maybe she looks at herself in a different way now; that she sees how great a person she is. Amazing…I have not thought about this before now…In 8 weeks she has not even once said: 'I'm not pretty'."

I-12:

"She has more confidence now; she has a strong personality... The only thing I've been thinking about is the time we have had to sit quietly and talk together; she has not been hushed down in the common room, as she often experienced in the past."

I-16:

"What has happened is that she uses words to describe herself when she tells stories, she may say 'that is me, you see', - and that is an identity."

Interlocutors were asked to compare the storytellers' expression of identity with that of others without an ID. 67% claimed the storytellers' expression of identity was different. 28% said the storytellers' expression of identity was partly similar to that of others without an ID (N:18). The interlocutors were asked before and after the LSW 'how clear the storytellers expressed their identity?' Their answers were:

Table 6.4: Changes in storytellers 'expression' of identity after LSW (%)

the scale	*pre-interview N:19*	*post-interview N:17*	*changes in storyteller's identity after the LSW*
5/superlatively	0	18	18
4/very good	63	59	- 2
3/good	21	23	0
2/bad	16	0	-11
1/very bad	0	0	0
total	*100*	*100*	*22 clearer expression of identity (NC/I/pre- and post)*

The table shows that interlocutors assessed 84% of storytellers' expression of identity to be good and very good before LSW, and 100% good/very/superlatively good after LSW. This tells us that something happened, especially to the 18% that were assessed to have a superlatively good expression of their identity. The importance of these findings is discussed further in chapter seven. It can, however, be concluded that the experiences of interlocutors gave them more faith in supporting people who struggle to find out who they are.

The interlocutors were asked, in phase two, how they thought they could encourage service users to achieve a lifelong development of their identity and personality. The interlocutors expressed some

noteworthy reflections related to their improved knowledge of the opportunities LSW provides. They were more aware of how important it was for adults with ID to have a strong and good feeling about their own identity and personality and that staff could help them develop this feeling. The interlocutors' responses on how they could encourage their service users are omitted. Some interlocutors however reflected, after LSW, on the differences and similarities between LSW and psychotherapy e.g. I-11:

> *"There is a connection to therapeutic issues, but I believe in everyday conversations and when we are together in a respectful manner, much of this (i.e. psychological problems) may be easier to tackle."*

Statements by interlocutors on LSW as a way to develop and maintain identity include:

I-4:

> *"LSW is very important... their identity, we have too little knowledge about it and it disappears… because they, for example, move. New staff do not write down this information, so it disappears just like so much history. "*

I-5:

> *"It is important that they have an opportunity to work with their own identity, to put some words to their experiences and have someone who listens to them...I see that she feels that she is the person she is... the things she has experienced and the importance of this...this is very important in LSW, so that they can express their stories and show them to others."*

Some interlocutors said that LSW makes it easier to understand the person and the person to understand themselves, e.g. I-17 said:

> *"I believe LSW is important to those who may have difficulties talking about their life and why they are 'as they are'. It may be easier to understand that 'I'm me' and to help people understand that life experiences have made them into who they are today."*

The findings in this section on personal development and particularly identity development are closely related to the changes the storytellers experienced in their own attitudes, knowledge and practice.

6.4 Impacts of life story work on interlocutors

This section outlines the influence of LSW on interlocutors, on their attitudes, knowledge, practice (their competence), which are important driving mechanisms in the person centred approach (2.3 & 6.5).

6.4.1 Attitudes

> *"One is humbled to be allowed to sit and listen; it has been a very thankful task. It is fantastic when the storyteller opens up as 'this' and seems to appreciate LSW so much." (I-1)*

Interlocutors were asked about the attitudes to users of services they thought staff should hold. A number said 'respect, equality and the importance of being listened to'. How the interlocutor talked with the storyteller was also considered to be important. They said a great deal more. This is, however, repeated in their description of changes in their own attitudes and is therefore omitted here.

94% of the interlocutors said their attitude to the storytellers had changed after LSW. Some said it had changed a lot (N: 16). The pairs also reported in their weekly reports (N: 14) about changes in the interlocutors. Changes they all mentioned were that interlocutors;

- Discovered more of 'themselves' and their behaviour in relation to the storyteller
- Looked at the storyteller with 'new eyes'; there was so much more 'inside' the storytellers, few remembering their past well
- Showed a greater interest in being well informed; - understood better why service users sometimes are frustrated
- Experienced that cooperation is more meaningful than they first thought

- Recognised the individual more; ‘before, I was the person that said that I understood - when I really didn’t
- Acknowledged the person’s potential to develop more, which was a totally new idea for some interlocutors
- Became more aware of the true significance of the small achievements made by the storyteller
- Acknowledged the importance of the storyteller’s past, were more curious about the childhood and youth of the service user
- Were more aware of the storyteller’s longing for a ‘normal life’
- Recognised the grief of the family when the child/sibling moved to an institution
- Had greater empathy
- Had more respect and understanding for the storytellers' limitations
- Looked at the storyteller in a more complex/multi-faceted way
- Were more galvanised to fight for them

95% of the interlocutors said they would fight for the storyteller’s interests and rights if there was a conflict between the service and the storyteller, even if this meant they had to oppose the manager. 53% said they had done this already (N:19).

Every interlocutor (100%) said they had a great deal of respect for the storyteller before LSW (N:18), while 53% said they had even more respect for the storyteller after LSW (N:15). Their respect was partly linked to the storytellers’ personal strength e.g.

I-6:

> *“…S-6 always gives 100% to others and she is tolerant and caring. She has some difficulties in her mind and that is challenging for her, but that makes her an example for many others - to have these difficulties and*

to be as she is - what she gives to others, she really works with herself. I respect her so much."

I-19/pre:

"I feel enormous respect because he still has his personality. He is totally dependent on help today but he has retained his personality. I respect him for that."

Interlocutors said that 'we show our respect in the way we talk to people'. They also said that it was important to be patient and explain things when service users did not understand, e.g. I-2 said:

"Often I hear the staff say: 'she doesn't remember- we have told her things so many times…' – when the staff say things like this I tell them that 'this is why she is here'."

Most of the interlocutors (67%) said they felt equal to the storyteller, but not in every situation. 17% of the interlocutors said they felt completely equal and 11% said they did not feel equal to the storyteller (N:18). 53% of the interlocutors said their feeling of equality had changed after LSW and most of them said they felt more equal than before LSW. Even those who said, before LSW, that they did not feel equal to the storyteller. 41% said their feeling of equality was the same as before LSW (N:17). Some said;

I-5:

"…we are listening to each other. Actually we are very similar, with one difference; I'm her supporter."

I-9:

"I'm not better than her. S-9 is older and has an ID, while I'm younger and do not have a disability; that is the difference between us... we are at different stages in our lives and are different in other ways too, but she is a human being equal to all other human beings."

I-15:

"I think we are less equal when I am thinking about the role I play … to say we are equal would be a lie… I have to be honest about it and say it out loud even if it is horrible…I am asking myself if I am doing the right thing and whether I have the right thoughts about 'this', or if I have become blind about myself. This is my feeling and I hope it does not become too apparent in my practice. But if I have a bad day at work it's probably easier for me to take over and decide too much."

I-16:

"I have another role here than she has, but we are equal yes, absolutely."

Other interlocutors valued their equality with the storyteller's life experiences e.g. I-2:

> *"When she talks, for example, about milk buckets, I know about these things, and when she asks me 'have you jumped in hay?' I can say 'yes, I have'. So I feel we have much in common, that we are not so different from each other."*

I-7 reflected on the connection between equality and respect:

> *"I like to think that we always have been equal... but I now see that she is indeed protecting herself... there are things she does not want to share... so respect is important."*

Some interlocutors related the question about equality to the storyteller's opportunities for self-determination:

I-15

> *"…a task has to be done. I think that this (LSW) makes an important contribution because we (staff) are not going to... lead the process, but let the storyteller have a fully self-determinative role. It is not easy when you have worked many years - and have your own way of doing things."*

I-17

> *"Now I'm more aware of the interactions with S-17, and also with others here. Even if we all are equal, there will always be situations where we are not equal - because we have different roles; I'm standing 'over him' in a way (she gives an example from shopping where she, in the end, made the decision). "*

Equality and that we value others is a part of peoples' humanity. Quotes earlier in this section on changes in interlocutors' attitudes towards the storytellers' ability to achieve personal development are more or less the same as equality in this section. Both are about seeing the people we work with through 'new eyes' and never taking people for granted. This may be the most important thing the interlocutors learnt; they changed their attitudes and received more knowledge….or the opposite!

6.4.2 Knowledge

Staff receive a lot of information about a service user in LSW. Staff thought this could be useful in the treatment and the prevention of illness. They also thought they had a better chance of preventing service users experiencing bad episodes when they knew their life story. Some interlocutors claimed that as people get older, they often become more isolated from other people. It therefore becomes more important to have people around you that know who you are and can talk about your life. They said that a number of service users had experienced being, in effect, abandoned and that LSW is one way of giving these people positive attention and understanding things about them e.g. their behaviour patterns.

> *"You have to know a person's life story to understand why the person is as they are and their behaviour - explanations!" (I-5/pre)*

The storytellers were asked who they thought knew most about them before LSW. They said (N:14) (%):

- Their family or one special person from the family: 43
- The staff, or particularly one service provider: 43
- A friend: 7

The interlocutors were asked how well they know the storyteller. One answered 'not so much', the remainder answering (N:19) (%):

- Only quite well: 42
- Well: 26
- Very well: 21

The interlocutors' answers about how well they knew the storyteller after LSW revealed, as expected, an increase. 89% said their knowledge had changed and 59% said they had much more knowledge about the storyteller after LSW.

94% of interlocutors said they had received very important knowledge about the storyteller (N:17). They said their understanding had

improved and they had a clearer view of who the storyteller was. They said:

I-2:

"Now I understand some of the words S-2 uses, which I didn't understand before."

I-6:

"We (staff) are sometimes totally 'blind'; we talk a lot together but mostly about the same things. Now we have opened some new 'drawers'. I understand much more now, at least I understand more of 'the material' that influences S-6's reactions and phobias… when we understand things, it is easier to accept and meet it with love instead of 'oh... not again!"

I-17:

"S-17 could previously react to things which I did not understand, but now I understand because I know S-17's history."

The biggest surprises storytellers gave interlocutors in LSW were;

I. How well or poorly the storytellers remembered;

I-10:

"It was amazing that she remembered the gifts she got for her confirmation over 30 years ago."

I-17:

"She remembered years and everything; I was so impressed and it came so fast that I almost couldn't believe her, so I checked and yes, she was right."

I-11:

"The first thing I experienced was that we needed help, we needed pictures and keywords about stories she wanted to tell about. I didn't know that she had such a bad memory….she is a person who talks a lot - most of the time, so discovering her bad memory before this was not easy."

Sometimes interlocutor observations were confirmed by the field-report. E.g. the researcher noted on the post-interview with S-11 that:

"S-11 was more present than in the pre-interview, but I have a feeling that she is in the early stage of dementia. She worked so hard to answer my questions."

II. How much interest, patience and endurance the storytellers had;

I-2:

"I was so surprised that she had talked about it to the staff in her home. I visited her …and had just opened the door when she phoned the residential staff and told them that she was doing this 'life-things'."

I-5:

"It surprised me that LSW was so important to her, also because it continued over such a long time …and that she prepared herself for the next meeting and took the initiative to do things."

I-9:

"…that S-9 didn't get bored, because S-9 doesn't talk very much…"

I-12:

"It surprised me that her stories came so fast and easy."

III. The openness and trust of the storyteller when they spoke about their lives; also about things they previously had trouble talking about;

I-14:

"When she talked about the pictures she was smiling… I am less afraid now to talk about S-14's childhood and family, I know more about it now and about the good things."

I-15:

"She was very sensitive about talking about the death of her mother before. But now, when we talked about this, she was not emotional, only positive. She told great stories about her mother and named her as 'my beloved mother'…she spoke freely and was relaxed about it."

V. How close some families and the storyteller's parents were; fabulous, kind and caring. The interlocutors said they had discovered how much the family had formed the storyteller's interests, behaviour and ways of thinking about life.

VI. The storyteller's potential for personal development. Some of the interlocutors thought this fact had been obscured by the focus staff had on 'caring for the person' and 'increasing their quality of life'. They discovered resources in the storyteller which were totally new and they recognised new opportunities.

I-14:

"S-14 improved her skills only after a few weeks, so there must be other things S-14 might only need time to 'take in…' there are more things I would like to find out; as we say 'the more you know the more you know how little you know'."

I-3:

"…about S-3's personality, I have seen so much more of that now. Most surprising of all was experiencing him as a conversation partner; how good he is at this when he feels comfortable. It's like day and night. That side of S-3 is something I wished everyone 'here' could see. I think I am the only one who has experienced it. I was completely surprised…It was a totally new side of S-3… I didn't think about his disability - the conversation flowed so well."

VII. The focus of storytellers in their LSW;

I-4:

"I was surprised by her way of deciding things, what she wanted to have in her album and what she wanted to talk about."

I-17:

"I thought he would talk more about his childhood, but no…he has been more interested in the institutions he has lived in."

I-15 had been the storyteller's key worker for more than 20 years and she was particularly surprised to learn about a friendship the storyteller had had since her childhood:

"She has talked a lot about JH (her friend for more than 40 who died a year ago)…that was touching because suddenly I understood... how close they had been, - like family. I had known about their friendship, but now I felt it."

VIII. How important it is to talk 'face to face' with service users in a secluded place

IX. The result of LSW; how easy it was and how proud the storytellers were. I-16 said: *"I thought it would have been so much more work, I was afraid it was too much work."*

Based on the 'LSW experts' experiences (4) the interlocutors were asked about their knowledge of the storyteller's tolerance limits, interests, values and life cycle.

Table 6.5 Interlocutors knowledge of the storytellers' tolerance limits, interests, values and life cycle (%)

interlocutors knowledge about the storyteller's	*before LSW*	*after LSW*
- tolerance limits	N:18 67 very good/good 33 only partial	N:15 74 more than before 26 the same as before
- interests	N:19 68 very good/good 32 only partial	N:16 56 more than before 44 the same as before
- values	N:19 37 very good/good 32 only partial 31 poor	N:16 62.5 more than before 37.5 the same as before
- life cycle	N:18 44 only partial 33 poor 22 good	N:16 100 more than before

The table shows that all interlocutors had greater knowledge of the storytellers' life cycle after LSW, which is not difficult to understand. More interestingly, 74% had greater knowledge of storytellers' tolerance limits after LSW, even though 67% said they had a good knowledge of this before. These findings may indicate that interlocutors can more clearly see storytellers' tolerance limits where the storytellers define and lead the process. They see tolerance limits more clearly than when they are sitting in the 'driving seat'. It is also interesting to note that interlocutors know more about the storytellers' interests than their values. Peoples' values are often more 'hidden'. Values may be more difficult to talk openly about than interests. So, these findings may indicate that it was easier to discover storytellers'

values in the process of working together in LSW and the LSW itself than in other types of cooperation they experience in day-to-day life. This may also be related to what storytellers' had told, that it was important to them to be listened to, to decide and to be alone with the interlocutor. This may also be generalised over to other parts of their interactions e.g. P-18/WR said that:

> *"The storyteller has the impression that I understand her better now… also when we have our weekly talks."*

The stories taught the interlocutors things about the storyteller they did not know, even though some had known the storyteller for many years (6.1). They experienced that the storyteller was more open and had fewer limitations than they had first thought. They were also surprised about the events and activities the storytellers had participated in. The interlocutors viewed some of the stories as very important in the coming years of care e.g. storytellers that had been exposed to sexual abuse should be treated carefully when they needed more practical help with personal hygiene.

After LSW, interlocutors spoke about the consequences of staff lacking knowledge about their service users' life stories, e.g.:

I-2:

> *"We have people that don't want to tell us about private things and I think if staff had knowledge about these things, they would have avoided a lot problems and hurt to the people they work with. This is knowledge the staff should have when they arrive for the first time in the people's home. It is a way of showing people respect - for the person they are and all the 'things' they have. Even if we learn about this in our education, we are not so good at doing this in practice, in peoples' homes. For me this is so important, I think everybody should have this. It (LSW) should have been a legal requirement of the job. It is so important."*

I-3:

> *"When we (staff) have knowledge of S-3's life stories, we may have a basis for conversation instead of just asking: 'did you have a good day at work today?' 'was the dinner good?', and so on."*

After LSW, the interlocutors spoke about the information they thought was necessary to provide good enough services, through their responses to the following propositions;

a) It is enough just to know the person's name, age and their diagnosis to provide a good service; None of the interlocutors' thought this was enough information to provide good enough services (N:19). Some of them explained why;

I-1:

> *"You need life experience…you learn from others when you work together. But there are things you need to know that are much more than this…attitudes and values are more important I think - than having a good knowledge of diagnosis."*

I-10:

> *"Knowledge about a person's background makes staff feel more comfortable - LSW helps with this."*

Some interlocutors said that previous records on service users were deleted when they moved into their homes, because staff wanted to start from scratch. They admitted, after the LSW, that this information could have been useful e.g. I-15/post:

> *"When you work with them, you do not think so much about their life story… when we hear stories from their childhood we hear things which are similar to ourselves and I see the value of the past more... family, happy childhood - good stories".*

b) One does not need a high level of formal education to be a good provider. The interlocutors (N:19) (%):

- Partially agreed (there is a need for both): 53
- Did not agreed: 26
- Agreed: 21

The interlocutors' point of view on education shows that there are no uniform views on this. Most based their answers on working experience e.g. I-9:

> *"There are well educated people in the health and social services that should not be working with people."*

6.4.3 Practice

Before LSW, most interlocutors said they had effective strategies for tackling their storyteller's anger and frustration. Most emphasised the importance of talking together and of being calm. Few interlocutors said their storyteller's anger was challenging and some said that staff had, in general, a low level of professionalism, e.g. I-14:

> *"It is so hurtful to observe staff who do not understand the 'things' (i.e. the pain) that are 'inside' the service users and see them reacting with discipline, force and correction, only recognising the service users' 'bad behaviour'. It is amazing that these people can work with people with ID. I think it's because of the low status of this work, the low salary and the working hours; so anyone who wants to can work with them."*

Interlocutors who spoke about how they make fun times with the storyteller had fewer suggestions on what they could do if the storyteller was frustrated or angry. Some also struggled with the storyteller's motivations.

88% of the interlocutors said they had changed their practice after LSW (N:17);

I-2a:

> *"Even if I feel stressed, I try to answer them in another way now."*

I-6:

> *"I have learned to listen in another way …I think the reason for this change is that I have experienced how important LSW is to S-2 and how important it is for her to ask and get good answers."*

I-15:

> *"I have been more aware of how she perceives and looks at things."*

The interlocutors had learned the importance of talking with the service users alone, in private and not just when they were together with everyone else (5.2.2 & 5.3.6). One interlocutor said her conclusion, after LSW, was that every service user needed 'one on one conversations' and not just 'group conversations', which was more common in her work.

They said it was easier to ask the storyteller about difficult things after LSW e.g. I-4 said:

"There are 'views' S-4 has not expressed to us before… very personal things which S-4 spoke about when the two of us were together."

Interlocutors said that they had learned to listen and to write down stories exactly as they were told and not use their own words to try to make them sound better. They had more access to the storyteller's life and some said they had moved to 'the core of the storyteller'; they had more knowledge about the storyteller's emotions and not just the events themselves. They had also knew more about which stories the person found troubling to talk about, and so gave the storyteller more time/space to tell about them. They experienced that the storyteller's word-flow improved as a result of this.

The interlocutors were more aware of their own communication and behaviour; they appreciated the storytellers more and gave them more feedback. They answered the service users more fully than before and felt they were much more at the 'same level'. They therefore also felt more professional. Some interlocutors said they had changed their role from being an 'educator', explaining and giving advice even when service users had not asked them for this, to being an 'enabler', giving service users more space talk about their decisions.

They were more aware of asking about the service user's thoughts, feelings and meanings and had a greater desire to listen to their stories. The interlocutors said that they, after LSW, were more aware about talking to service users who sat alone and apart from the group. Other staff also observed changes in the LSW participants and a greater interest in the service users' stories.

I-1 gave a concrete example of a situation, after LSW, which staff caught because they had LSW knowledge:

> *"There was a service-user who had his camera with him for a number of days and one day we asked him if we could look at the pictures he had taken. We, very quickly, put up a big screen so everybody could see. I think this was important and it is something we should have done more for each of them. It is important that service users get the attention they need, so they can feel valued and grow personally…"*

Some interlocutors told how they helped the service user to find words when they wanted to say something. One said the storyteller was not hushed down in the common room now as she had been before. They told how they defended the storyteller, how they had used the information from LSW to explain the storyteller to the other staff. They said the changes had contributed to a better and more 'appropriate' service for the storyteller, e.g. I-11:

> *"We had a staff meeting and I felt they talked about S-11 in a different way than the way I know her, so I said what I know - this was an easy way to help her in a good way."*

Interlocutors were more aware of their lack of information on the storyteller and the importance of asking them about this. They were more sensitive (they understood better) the storyteller's body language and their signals e.g. by asking 'what is happening to you now?' They were also more aware of distress and the storyteller's verbal communication; more present so better able to 'see and hear', more reflective and better able to ask questions to find out more and understand better. They had improved their observation and reflection skills e.g. 'when you told her that, she did that, why do you think she did that?' and said they were better at holding focus on important things. They had improved their skills in ethical discussions and viewed this in a bigger context to improve what they did for the service users.

Some of the interlocutors said that before LSW, they gave up much quicker when storytellers did not respond and that they had viewed ‘self-determination’ as a hindrance to their role and work. After LSW, the interlocutors viewed self-determination differently and had discovered how small steps could give personal development and behavioural changes.

6.4.3.1 Relationships and communication

The interlocutors spoke about how much closer they felt to the storyteller after LSW. Even where they had known each other for many years and had had good contact. They said the relationship between them had improved and was better than before;

I-1:

“I sit more with him I think. For example, when choosing where to sit, I would choose him before the others because we have established a kind of bond - something has happened between us. We have something in common, something we have done together that only the two of us know about. “

I-4:

“We have another kind of communication between us now...she might feel closer to me now than before...and I to her; I have not worked as closely as this with her before, so we have achieved better contact and she is coming to me more often now than before; she is asking me about things and waiting for me to respond. “

I-6:

“The interaction between us, which is so important, has been stronger – the LSW made it stronger.”

P-7/WR:

“It is easier to look in each other's eyes now. For my part, I feel something has happened to me as well; I know myself better and I am thinking more about how I am towards her…we have a feeling of really good contact… Lately I have stroked her back more often, tried that type of contact and she has done the same with me. Today, when we said goodbye, I hugged her quite spontaneously and she stroked my back and smiled. I am thinking; this would not have happened if I had not responded first, but it was a positive thing for both of us. She is, to a great extent, at the mercy of the initiative I take. I am not going to underrate her, however, she is quick to follow up. But there is something about the balance between us…I mustn't put words into her

mouth or activities in her lap. On the other hand, she needs someone to help her get going."

I-11:

"Something has happened between us; I may see her clearly and more often now, and I prioritise her more than before. I give her more feedback and I know when she needs help…I can recognise that more now… now, I see 'the whole her' in another way, she has become more of 'a whole person'. I recognise that she now finds it easier to speak to me...and I answer almost as if she were a colleague, yet at the same time I have in my head that she has an ID and needs clear answers."

P-12/WR:

"We have known each other for many years. I have been her key worker for a number of years…After this project started, I felt we became even closer - there is a 'something' that we share, just S-12 and I."

The following pictures show examples of the relationships observed between staff/interlocutors and storytellers at closing parties:

27

27: The storyteller is, because of her legs, sitting; the interlocutor is standing and holding the album so the storyteller can tell about her family tree. The interlocutor asks her questions to help her remember (PICT0099).

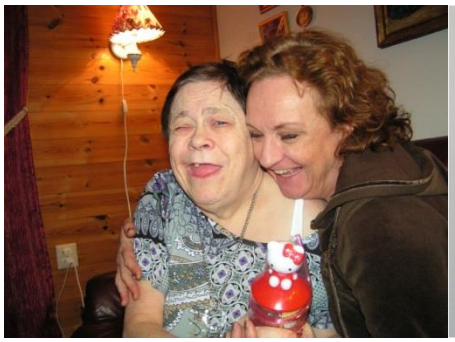
28

28: The interlocutor is standing behind the storyteller and holding the album. He is sitting because of the pain in his legs. The man has few words but the interlocutor is holding the microphone in front of him and helps him tell about the pictures and stories. (PICT0050).

29: The interlocutor is holding the album and standing beside the storyteller as he tells stories from his album (PICT0066).

29

Confidence is a basic element of a good relationship. People who feel confident also feel more relaxed about saying whatever they want to say and give natural physical responses such as a hug:



30 (PICT0113)

31 (PICT0071)

The pictures above show some of the relationships observed between storytellers and interlocutors. Respect, happiness, support, humility and some of the unspoken part of a good relationship are shown. The storytellers confidence and pride is particulalry evident.

The good relationships were confirmed by the participants when asked how they experienced the cooperation between them in the weekly reports. One participant, however, said (P-3/WR):

> *"The cooperation has not been as good as it could be and it is I (the interlocutor) who has failed. There have been many times when I have had to change the day and the time of our meetings, because things that happened making it impossible for me to keep my appointment with S-3. Of course S-3 has been disappointed and it has been hard to see this and his frustration. It is not a good feeling."*

Good communication is a condition for good relationships. The interest interlocutors showed in their storytellers was also confirmed by the 'communication' findings; 74% of the interlocutors said they had good and very good conversations with the storyteller before LSW (N:19). 82% however also said that communication had improved and changed in a positive way after LSW (N:17):

I-16:

"I have a type of dialogue with her that I never had before."

I-3:

"It is about knowing which buttons you can press to get a response….he 'reads' you very clearly and knows whether you understand what he is saying - or not."

I-15:

"She tells me sometimes that it is easier to understand when I explain things for her; that is lovely to hear because I then understand that I'm able to communicate at her level."

I-4:

"We have been more confident… when she wants to talk with me now, we pull back a little bit from the others...so not everyone can hear what we are talking about."

People feeling *confident and safe* together is also a condition for good relationships. Before LSW, 79% of the interlocutors said they felt very comfortable and safe together with the storyteller (N:19). Even so, 76% of the interlocutors said these feelings had changed and increased after LSW (N:17). They said:

I-1:

"I felt safe before as well, but I feel safer now and that might have something to do with the fact that we know each other better. I can joke with him now, which I couldn't do before."

I-11:

"My confidence has increased and I feel more at peace."

I-12:

"She is more tolerant of me now."

A number of pairs said, in their weekly reports, that LSW helped them to talk with greater ease about difficulties, e.g.

P-6/WR:

> *"We cooperate in a more meaningful way, in the sense that I react to S-6´s reactions and behaviour in a better way. I take part in S-6´s experiences and take part in her life; her care for herself, persons that are close to her and so on."*

P-18/WR:

> *"S-18 has really opened up and gives the impression of feeling comfortable in this situation. S-18 said to me 'I can tell you everything!' - Hearing that was so good for me - it means that she trusts me."*

Another condition for good relationships is that people are *interested* in each other. Every interlocutor (100%) said, in pre-interviews, that the storyteller was a very interesting person (N:17). In post-interviews, 76% thought the storyteller was even more interesting than before LSW (N:17).

The next section outlines the interlocutors' assumptions about the usefulness of LSW in the person centred approach to services for older adults with ID.

6.5 The scope of life story work in Norway and its relevance in today's services for older adults with intellectual disabilities

Some data in this section comes from 'LSW experts' and some form storytellers and interlocutors. This small but important topic is related to LSW. It was, therefore, important to find evidence in correlations in emergent patterns within the experimental material from all participants.

We find LSW to be one factor in the definition of PCA (1.4). We also found, in phase one of this study, that LSW is not frequently used in

Norwegian services for adults and older adults with ID (2.7.2). The interlocutors were therefore asked in phase two and based on these findings 'why it this so?' - why is LSW not more frequently used in Norwegian services for people with ID? (N:19) (%):

- The service providers lack knowledge on LSW: 42
- The service did not have enough resources (money, time etc.): 32
- The service providers lack interest in LSW: 26

The interlocutors also said that municipalities lacked flexibility that it took too long to change established routines and that 'something' or someone always stopped a development change. Some thought LSW was viewed as a waste of money, while others said there were enough resources if they were used in the right way. Other quotes include (anonymised to protect the interests of informants):

> *"It says something about the lack of interest in the person's life... service users are totally ignored and information about them is kept in archives....and even this information is not their story or their words; it is all written by GP's and staff."*

> *"…there is still an attitude that it's not important because they have an ID, so what can they say about themselves and their life? My experience is that there are many people that think 'this is just something they say, nothing is true'. They are often stopped when they try to say something, all they hear is people saying 'no, don't talk about that now.... that was a long time ago', and things like that...staff don't take them seriously….a sheer ignorance of those who work with them. Of course it is just as important to them as it is to us, to talk about these things, - even more to them I think. For example …if you know her, you also know which questions you can ask...you can't ask 'can you tell me about Vestlandsheimen?' "*

Before LSW, all interlocutors (100%) in this study said LSW was important. 84% of these said LSW was very important (N:19). After LSW, interlocutors' scored how important they thought LSW was in PCA using a scale of one to ten (ten was the highest score) (N:17). All gave scores of between eight and ten, some saying:

I-1:

> *"Older adults with ID forget quickly - yes, many do. It's important to them to look in their album, movie or whatever… also that they are alone with us two hours every week, making a book etc. Not everyone has the opportunity or capacity to do this - but it is so important; not*

only is the product important - the whole process is important…"We (staff) are stupid if we all make the same mistakes with service users….so the answer is… - we need more knowledge about service users' lives."

I-2:

"I have always thought the past is important and I think it is not as important to know everything about their desires and all those things as to know how their life has been; whether there have been things that have been difficult… to give the staff the opportunity to say 'I understand that this is not easy for you' and 'I understand that it was an exciting event' or 'I understand that you have had different life experiences than the others'."

I-6:

"LSW should be there from the start when they move into a home… It should be a requirement that it is done within the first year. If I had known in the beginning… twelve years ago, the things I know today, then things would have been different."

I-15:

"LSW is a good tool for older adults; LSW is a way to understand them and a 'tool' they can use to tell about themselves, LSW is particularly important to those who get sick."

I-19:

"It should be a part of everyday life."

The interlocutors also said LSW is useful in the 'hunt for lost lives';

I-3:

"If we had this (LSW) when I started here, it would have been completely different. …it is difficult that nobody knows where his case papers/reports from Vestlandsheimen (HVPU-institution) are. We have tried to find them, but nobody knows. Maybe they are in an archive somewhere?"

I-4:

" Some of them have no recorded history... their background is unfortunately not written down in their records…someone may tell about something or someone knows something - you may in this way get small pieces that you can put together…and no-one has ever taken responsibility for writing it all down. Their history is lost. Yes, and they do say different things to different people every time...they may tell one thing to me and another thing to another person - right?"

I-6:

"She has moved a lot and the question is how much information has moved with her - what she and her staff have talked about..."

I-19:

"Many of them have a past that is forgotten, they have lived with a lot of other people and a lot of staff…many of them do not have family that can tell about their past, unfortunately the past of many of them has been erased…it is so sad. So LSW is so important in finding out what is 'there'…LSW is not only important when they are older, they should do it before and it should be followed up throughout their lives... if you can't see yourself you get lost."

Interlocutors also learned that the information provided by the storytellers was more precise and comprehensive than from other staff and from records e.g. I-3 said in the post-interview:

> *Interlocutor:* I can see that I have been a very poor conversation partner for him all the years I have been here. When I started here, I would have liked someone to have told me all the things I know today. It would have been so different. Many of staff had a moment of realisation when looking in his album; it contains a lot of information that was new to them
>
> *Interviewer:* Staff who have been working here for a while?
>
> *Interlocutor:* Yes many of them. And of course, you have to know about things to use this in a conversation. You have to ask more directly about certain things, if you ask too open or general questions he gets stressed…The fact is that 80% of us who work here lack basic and necessary knowledge/information
>
> *Interviewer:* How do you think this lack of knowledge affects the residents?
>
> *Interlocutor:* They are so used to it; they don't know anything else…

Different ways of using LSW have been suggested by the 'LSW experts' (N:6) in phase one (4) and by the interlocutors (N:14) in phase two. Experience of the usefulness and benefits of LSW include:

a) In conferences; give storytellers a microphone and let them talk about their life, so listeners gain knowledge and understanding
b) At work or in leisure time; find out about a person's background, resources and wishes
c) As a basis for a CV; when applying for jobs
d) In bereavement e.g. when someone has died; use stories and pictures to remember and talk about the deceased person, to deal with the grief
e) When a person is seriously ill or is dying; use the person's album to help them look back and summarise their life or to acquire information about their wishes, what they like or do not like...

f) As a basis for IP; information on the person's history, personality, needs, wishes etc.
g) As a vehicle to go forward in life; to gain knowledge/insight of own skills, aspirations and attitudes that might stop or help a person go forward
h) To 'wake up' sleeping networks and build social networks; old friends may become new friends and families reunite
i) Introductions to new staff; a tool for service users' to present themselves to other/new services and neighbours. An album or an interactive DVD can help people who lack verbal language to show their history independent of others
j) LSW could result in valuable information for a GP and important information in a person's journal (if the storyteller permits this)
k) Reminiscence; a 'stay with us' approach for people with dementia
l) In hospital; valuable information about a person's personal aspirations may be used in holistic treatment
m) A tool for interdisciplinary work - to ensure that service providers have the same (and sufficient) knowledge about their service users. Some people with ID are not able to express themselves clearly enough. LSW may be able to provide information they otherwise are not able to communicate
n) A 'moving document'; when a resident moves to a new place, to ensure their new support staff are well informed about them
o) To provide historical data e.g. about a closed institution; (former) residents may tell stories about their childhood at the institution, old photos and help interview other, old members of the staff group

p) LSW may help families that are troubled by their relationships; they could create their family history together and in this way help themselves to understand better and to be closer to each other.

88% of interlocutors (N:16), 94% of the storytellers (N:18) and 67% of pairs (in their weekly reports /N:15) said they wanted to continue with LSW after the project ended. This means that between 83% and 91% (only pre- and post-interviews) of participants said they wanted to continue with LSW. Some said;

I-3:

"A spontaneous reaction in our staff group was that this is something everybody should do…it is about priority, now we have set aside time for it, but it is not easy. I have become even more aware of the importance of doing things like this."

I-6:

"I'm going to conduct supervision and appraisals to establish a team around S-6 - the 'new knowledge' is 'like gold'. We will make a little handbook from the LSW, considerations and explanations of 'why', - then people hopefully will understand…"

Some wanted to continue LSW as long as there were stories to tell and to include it as a part of their weekly conversations, e.g. P-15/WR:

"This is a good form of dialogue and way of speaking about things that S-15 is interested in, and for me also, to listen to her stories and memories."

Interlocutors were asked about how LSW could be established in the service. Most gave the same sort of reply as I-11: *"...to see the change in people as they do LSW and become more 'a whole person'...my colleagues have seen the value of this… It is so important to see the results of LSW - that is the biggest motivation."*

A number of interlocutors said the result of LSW motivated other staff to do LSW with other service users. Key workers in particular said LSW could be beneficial.

They also said it could be challenging, e.g. I-6 said that: *"Finding the time is a problem, but we can't afford to not do it, we could do it 2 hrs every week in one month. It might make our work easier and more interesting/motivating; perhaps we would see less sick leave amongst staff?"*

Some interlocutors said it all depended on the staff. Staff could carry out LSW if they wanted to and valued it highly enough. This did not, however, apply to users. They needed help to do LSW. It was also suggested that money could be applied for, to run life stories as a project. Service providers have said that less money is now made available to the services than before, leisure activities particularly being adversely affected. The interlocutors suggested that strong service user interest in LSW and the engagement of the staff group and manager could bring about LSW establishment in the service (N: 16). Some suggestions were;

I-8:

> *"Everybody should do this every week. …and it should be a legal requirement… there is no system for this …no one takes responsibility. They need someone to 'see' them and they need time with us, time when they do not need to share us with anyone else."*

I-11:

> *"... I think the vision for LSW should be given much more prominence; it should be a much greater priority … It is so important, the impact of this work should be published in our sector, but also to other people and services, that would increase competence and understanding and may also increase the chances of getting resources allocated to this type of work."*

6.5.1 Individual Plan versus life story work

An Individual Plan (IP) is a legal right in Norway and a well-known tool in PCA (2.3). In phase one; ex-2 said that an IP must be based i) on personal goals, ii) on an understanding of themselves and iii) their personal development. This person has been saying this for more than

15 years. 'His' organisation has only used IP but included life stories into IP. Ex-2 explained:

> *"These life stories… use of an interactive CD on a computer, may help people present themselves, what they want to achieve, what their concerns are and what their fears are - an IP should reflect the life story issues."*

One issue in phase two was the use of IP in Norwegian services for older adults with ID. Interlocutors were asked whether they used IP in 'their' service. All (100%) answered 'no' (N:17). Storytellers were asked about what they knew about IP (N:18), 89% said they had never had heard about 'IP'. 11% said they had heard about it and one of them said they had an IP but could not remember what it contained (S-1/pre). These responses mean that there is a huge lack of IP practice in services for older adults with ID, also in other parts of the service (see 2.3). There must be a reason behind service providers not using IP and service users not demanding their rights to IP. It is not possible to say more about this in this study. Exploring IP in relation to LSW has, however, been important.

Interlocutors were asked about the importance of LSW compared with the importance of IP. Their answers were (N:19) (%):

- LSW is more important than an IP: 58
- Both LSW and IP are important: 32

Some interlocutors said;

I-2:

> *"I believe that LSW is the story of the past and present and the person's experience of this. I feel IP is more for the staff, who need a plan for the future - this doesn't mean a great deal to our service users. LSW is about the person in a way that is different to IP, in IP a lot of other people have opinions."*

I-6:

> *"IP is a tool for interaction and collaboration while LSW is the basis for IP… It should be included in the municipalities' quality system, as important as fire regulations, something they have to do...I have told everybody that LSW will come up now... it should be used instead of IP... they are the voiceless that we are not used to listening to."*

I-8:

"In LSW the user is in charge and has control, IP is often about health and we are deciding much more."

I-15:

"LSW is more important because you get closer to the person and it is based on their own stories - we can make a good IP from it … I think it increases our professionalism."

I-16:

"You may need both, you need plans too. You get a bigger picture when you also know their life stories, which I want to do for her; because I have too little knowledge about her."

I-17:

"IP and LSW are two very different things. Service users have control In LSW and decide what they want to tell. In IP, the service user's needs are often defined by people other than themselves."

I-18:

"An IP is more about the future; LSW is more about the past and everything else."

I-19:

"IP is a different kind of work; LSW is much more the user's. I think that is important. They are setting the agenda and deciding what we are going to do and how we are going to do it."

An IP contains future goals for the service user. Interlocutors were asked in this study how clearly they thought the storyteller could describe their desires and goals (2.6.2). Their answers could indicate the storytellers' ability to discuss goals and desires in relation to an IP. The results shows that 72% of the interlocutors in the pre-interviews and 81% in the post-interviews said the storytellers expressed their goals and desires in a clear way. Only 28% in pre-interviews and 19% in the post-interviews said the storytellers were not able or did not express their goals and wishes in a clear way. The interlocutors were not asked to explain 'why'. A comparison of data from pre- and post-interviews shows a change. 9% more storytellers expressed their goals and desires in a clear manner after LSW. This means that storytellers that participated in this study are able to carry out LSW and participate in developing their own IP.

6.6 Summary

This section outlines important findings in interlocutor experiences associated with their LSW. Important contextual impacts, mechanisms, outcomes and phenomena are described to show emergent patterns (i.e. themes), convergence, divergence, commonality and nuance emphasised in the collected experiential data material. Experiences and opinions that relate to individual cases are visualised in quotes. Tables are used to show variations between interlocutors and comparisons between interlocutors and storytellers. The participants' experiences are drawn together at the end of section 6.5 to make comparisons. Most findings in this section are discussed further in chapter seven.

The demographic and contextual attributions of interlocutors show variations in gender, cultural background, ages, education and roles. They can be considered to be representative of service providers for people with ID. Interlocutors' experience of structural and practical LSW conditions shows issues that relate to LSW in general. These themes can be experienced in a number of LSW approaches, emotional challenges in particular. Other issues relate to the LSW programme in this study, such as plans and meetings between the pairs. There was amazingly little criticism of the process or workload. The comment written by P-5 in their weekly report summarises well the experience of all the storytellers and their interlocutors;

> *"We think that we have had some good times together, and we have got to know each other better. It has been a nice trip through the past, the present and the future."*

Findings in this section represent a basis for understanding the impact of LSW on both storytellers and interlocutors.

The interlocutors' experience of their storytellers' personal development can be related to what storytellers told about personal development. Exploring these phenomena from both sides gives a deeper understanding of the impact of LSW on storytellers' personal development. The emergent patterns in this experience can be said to be both contextual and the 'driving mechanisms' behind the evident data on storyteller personal and identity development. Interlocutors' experience of storytellers' feelings of confidence and self-respect can be affected by interlocutors' opinions on development in older adults with ID. Being able to remember and being listened to may also have an impact upon this. Storytellers' ability and freedom to self-determination also constitute important findings in the experimental material from interlocutors. These experiences may also directly affect the interlocutors' experience of storytellers' personal development, particularly identity development.

Statements from the interlocutors on the impact of LSW on their attitudes, knowledge and practice (defined as personal development of competence), constitute central findings in the analysis of the experimental material of this thesis. Emotions and relationships between the participants in this study became an important issue, which may challenge the professionals in this field. The interlocutors' increased knowledge of the storytellers' life circle, values and interests are important findings that are discussed further in chapter seven.

The findings on the scope and relevance of LSW in Norwegian services and the relationships and weighting between LSW and IP are important contributions in PCA and are discussed further in the next section.

7 Discussion

The findings of this study imply innovative knowledge about how life story work supports storytellers' identity development, interlocutor competence and the person centred approach in services for adults- and older people with ID. An innovative model of LSW was developed and findings may add new perspectives to social and psychological theories, which often are related to people with disability.

The structure of this section begins with a discussion of the impact LSW has had on the storytellers in this study (7.1.) and on the interlocutors (7.2). These two sections provide sufficient evidence to support a discussion of the potential adoption of a Norwegian LSW-model in services to people with ID (7.3). Section 7.4 is a discussion of social, political theories and strategies related to the findings in this thesis and discussions about the road from research to politics and practice. The last section (7.5) contains a reflective account of the research process. The discussion leads directly to a conclusion (8), which is the last section in this thesis.

7.1 Life story work benefits the storytellers' personal and identity development

The research found that about the half of the storytellers in this study were not accustomed to talking about their life stories to their staff or other people (5.1)[38]. This is a significant finding, considering that services are supposed to be individualised and that all interlocutors thought LSW would mitigate psychiatric problems (6.3.3).

The literature study and the interviews with the 'LSW- experts' in phase one confirmed that LSW is not commonly used in Norwegian services for people with ID (6.5). Conversations with managers of some of these services and who were the gatekeepers in phase two confirmed that LSW was new to them and that the importance of learning about and understanding service users' life stories was not emphasised to services staff. They were surprised they had not thought of LSW before.

One main finding in this study is that 69% of the interlocutors said that storytellers' identity had been clearer (or strong) after LSW. This is despite 58% of interlocutors saying they had a strong and clear identity before LSW (6.3.5.1). This result indicates that even interlocutors, who observed 'identity strength' in the storytellers, viewed this strength differently and in more depth after LSW. This was confirmed by statements made by the interlocutors (ibid).

[38] The question was whether they previously had told staff or others about their life, not if they had done LSW before.

Another explanation of why storyteller identity changes and becomes more visual and stronger after LSW (22% more) is that LSW has an impact on people's feelings about themselves and how they express their identity (6.3.3-5). A strong feeling of who you are makes you more aware of what you like or do not like and increases self-determination. It may also protect against discrimination, devaluation and abuse from other people and systems (Svendsen 2004; Svendsen 2012; Söder 2009).

It is suggested, based on the view of ecological models, that changes in a person's behaviour may be explained by environmental changes (Stubrud 2001). One exceptional environmental change experienced by the storytellers in this study was being alone with one member of staff who actively listened to the important events in their lives. Another influence may be that the LSW programme emphasised the creation of an optimal situation in which storytellers could use their resources in an optimal way. This again led to new situations and relations in which storytellers improved their skills. They experienced a virtuous circle of storytelling about the past, which benefits how they feel in the present and which is an important factor in the success of the work.

7.1.1 The benefits of life story work related to the feeling of being listened to and remembering events in life

Arguments for the importance of being listened to are found in a democratic society, in the therapeutic field and in day-to-day life between people. A good conversation is a dialogue where the participants are listeners because they are interested in what is being said (2.8.4). People with ID have historically and in general not been listened to (1.1-2). This study shows they are still not listened to (table

5.5). Some interlocutors said the storytellers were ‘starved’ of others listening to them and giving them attention (I-4 in 6.3.2). One storyteller said that a storyteller self-harms when people are not listening to her (S-5 in 5.3.2) and an interlocutor said (6.3.2): *“... they are the voiceless ones that we are not used to listening to.”*

One of the most important purposes of LSW in the UK has been to give people with ID ‘a voice’. A ‘voice’ that raises awareness of their experiences based on their different backgrounds and personalities (Atkinson, Jackson and Walmsley 1997; Hussain and Raczka 1997; Meininger 2006; Potts and Fido 1991).

There was evidence in this study that LSW changed the opportunity storytellers’ had to be listened to, to have a ‘voice’ and to visualise their life stories in e.g. albums, memory boxes etc. The closing parties in particular became an unexpectedly important arena for sharing stories with others. For example with managers from the municipality and the media (3.7.2 & 5.2.2).These parties were, in general, surprisingly more valuable to the participants’ than I anticipated. If this study is repeated, then information should be collected from closing parties. This potential will be built into the model when it is published in a book with accessible (Norwegian) text by Universitetsforlaget in the autumn of 2016.

Nigel Ingham writes on the website for the project ‘*Unlocking the past, Community Service Volunteers’* (http://www.unlockingthepast.org.uk) that when people with ID experienced being heard and listened to, then this contributed to an enhancement of their feelings of identity and self-confidence, pride and self-understanding and moderated their feelings of guilt and shame about the past (Ingham 2006). In some studies, people with ID have said their motivation for

telling their story was to prevent things that happened to them being repeated in the future (Atkinson, Jackson and Walmsley 1997; Ingham 2006; Potts and Fido 1991; Townson et al. 2004; Tuffrey-Wijne and Davies 2007).

In this thesis, it is not possible to say whether LSW moderated the storyteller's feelings of guilt and shame, as this was not a topic or a focus of exploration. They did, however, feel better about themselves, became more open and spoke more about themselves (6.3.3 & 6.4.2), which also is confirmed in other studies (Meininger 2006). The interlocutors' observation that storytellers felt more important than before is an important observation on the impact of LSW (6.3.2). This feeling led the storytellers to tell more stories and to speak more in groups with other people (6.3.5.1). A potentially fruitful area for further research would be to 'validate' this interpretation by following some of the storytellers onwards and measuring the long-term effects of LSW.

7.1.1.1 The benefits of looking back on own life

The act of remembering one's own life is crucial to a sense of the self and is a means of maintaining self-identity (Atkinson 2004; Buss 2001; Woodward 2002). A robust sense of self and who we are has been found to be associated with reductions in anxiety, depression and aggression (Engedal and Haugen 2004).

Peoples' memories are not neutral registrations. They are selective. Some things are remembered and other things are beyond reach, in 'black holes' or 'white spots'. Professionals still do not have an answer to the question of how identity and self-perception are

influenced by brain damage. Brain damage can make it difficult to remember and put life events together in chronological order (Gjærum and Ellertsen 2002; Thorsen 2005). Other questions are to what extent can a dialogue produce stories from the past and how do people communicate feelings and reactions from their past when their vocabulary consists of just a few words limited to simple items, rendering them incapable of using terms to convey ideas or emotions?

Some storytellers in this study said they felt insecure when they could not remember things. The interlocutors, however, spoke about the completely new situation for storytellers of being able (with the help of their albums) to remember their stories. They were clearer when they talked and they acted more confidently in group settings. They started to tell new stories which those around them had never heard before (5.2.3, 5.3.6 & 6.3.2).

Pain and loss are an integral part of looking back. Mixing this together with good memories and good conversations can, however, make it all worthwhile. It is often easier to talk about sad memories if we accept that they are a part of peoples' past. Some interlocutors found that the storyteller did not want to talk about certain periods of their life. It was important that this was respected (6.2.3). The researcher did not ask the storytellers about these periods. Some interlocutors however said they understood that shame, anxiety, sexual abuse, depression and hurtful/demeaning treatment or aggression were emotions they related to these periods of their lives (5.3.2 & 6.2.3). Other studies describe those separated from their families and sent to big institutions early in their lifespan having an emotional blockage because most of them experienced this as a frightening and confusing event (Atkinson, Jackson and Walmsley 1997; Johnson and Traustadóttir 2005; Thorsen 2005).

The interlocutors were impressed by how well some storytellers remembered things and also how poorly others remembered (6.4.2). Poor memory is not a characteristic particular to people with ID. There is a risk of dementia, especially for those with Down syndrome (1.1.1), which was an issue for one storyteller in this study (6.4.2). Dementia was an exclusion criterion (3.4) and the storyteller and the interlocutor had no knowledge of the dementia when they started LSW. This story tells us that LSW may be a way for service providers to understand more of the service user's memory loss when they observe a change in their behaviour. Talking about their life is a way to understand what kind of memory loss the storyteller has and if there is an onset of dementia. All the interlocutors in this study thought LSW was useful for people with dementia and that it could help mitigate psychiatric problems, which are also frequent among people with ID and people with dementia (1.1.1 & 6.5).

7.1.2 The benefits of life story work related to the ability to raise awareness of life choices, liberty and human rights

The historical section (1.2) shows that many Norwegian older adults with ID (and in other countries) experienced violation, abuse, little freedom and lack of educational opportunities when growing up and also maybe later in their lives. Many of these people never realised their potential and never had the freedom to find out what they are good at and what they would like to do with their lives.

Several of the older adults in this study talked about painful experiences from the past (5.3.2). Most today felt safe and free to do what they wanted to do. Only 18% of the storytellers' in phase two told about being dissatisfied with their freedom and opportunities to

do things alone with or without a staff member. 43% told they felt staff stopped them from doing things they liked e.g. visiting siblings, eating food, being together with staff. They also stopped them or persuaded them from doing things they wanted to do in numerous 'day-to-day situations' (5.3.4-5). Some however also talked about the 'duty we all have' and which prevents us from doing some of the things we like to do. Some storytellers used this as a type of explanation of why they stopped doing things they liked to do.

Some of the interlocutors in this study talked more about the storytellers' lack of freedom than the storytellers did. They also, in this context, talked about the 'care regimes' which a clear majority of storytellers appear to live under in today's services (Brevik and Høyland 2007).

It is not known why the storytellers did not talk more about their lack of freedom. However, 63% grew up in an institution. Their experience from Norwegian institutions did not include stories about opportunities and freedom (1.2). So are their current life experiences better 'now'? Is 'there nothing to complain about' now? They may not know how to complain, as none of the storytellers in this study had any knowledge of their rights in public services (5.3.7). Or maybe, as one storyteller said, 'It is important to keep going and not let bad things take over our lives' (5.3.2).

In phase one, ex-1 spoke about how important it is for service users to get an overview of their life, to feel free and move on with their lives (4.3). Other researchers say that LSW enables people to accept past events, losses and grief and move forward towards building a more certain future for themselves (Hussain and Raczka 1997). This was evident also in this study, as the findings presented in sections 4.3, 5.4

and 6.3 show. This is an important reminder to staff to use storyteller history to understand the storyteller, but to also move on from this and let them look forward to their future life.

The experiences of the older adults in this study seem to have made them strong as people. They have a kindness and warmth that the researcher could not fail to be affected by and which the interlocutors were also affected by (6.2.5) and appreciated in their conversations. We might consider that the acceptance and appreciation of the interlocutors had an impact on the storytellers' lives and view of themselves. This could not be proved clearly in this study.

7.1.2.1 The liberty and ability to make own choices

Liberty and empowerment are much the same thing. To encourage self-determination is one strategy to make people feel more free and empowered. Assumptions behind this include that people already feel confident and have some knowledge and skills (2.2).

Empowerment practices in Norway represent a relatively new experience for many older adults with ID. Younger generations have grown up with these ideas and have greater expectations and greater skill at claiming their rights. Older generations have less experience with the idea of using individual responsibility to claim their rights and deciding things in their lives. The idea of empowerment in services in Norway is evaluated to be poor (2.2). This is confirmed by this study. On average only 55%-67% of the storytellers said they decided things in their homes (5.3.5). Explanations for this may include a past history of learned passivity/helplessness, a lack of staff time, a lack of self-confidence, training in how to make good

decisions in life and the prevailing attitudes, knowledge and practice of staff (6.4).

Just 16% of the interlocutors however said service users did not have the opportunity to exercise self-determination, a figure which rose to 32% after the LSW (6.3.4). This shows that the interlocutors believed the storytellers had much more opportunity to practice self-determination than the storytellers. These results appear a little strange when related to most interlocutors saying that service users were stopped by the 'care regime' they lived under.

The intervention in this study emphasised the storytellers' opportunity to exercise practical and real empowerment (3.2.2 & 3.7.1). The results described above however raise the question of whether LSW has increased their sense of self-determination, achieved through the support of the relationship developed with 'their' interlocutor through LSW.

The intervention also provided interlocutors with training in empowerment strategies. The programme is designed to involve and empower participants (participatory practice) and is based on the information which the storyteller has decided to share. This information was quite different in some cases from what staff thought participants needed to talk about (6.4.2).

Trust and confidence was built between LSW pairs. We assume that 'vulnerable older adults' find it easier to talk freely in these meetings and be supported in claiming their rights and expressing their wishes. Storytellers had, in their LSW interlocutor, someone who both listened and could tell the staff group things on their behalf if they both decided that this was acceptable.

Other studies in this field also report that older adults achieve increased self-esteem and improved communication skills, important aspects in increasing empowerment (Heathcote 2009).

We may think, from the perspective of older adults with ID, that their impairment hinders them from feeling free to do what they want or from leaving a troubled living environment. One storyteller said that their lack of knowledge affected their capacity to act (5.3.2). It is easier for the interlocutor to enter into a discussion with the storyteller 'there and then' when such stories are told in LSW. A common response in other settings is 'wait, wait' (6.3.2). LSW gives the storyteller the chance to discuss the consequences of their disability and maybe to find some answers. Other researchers say that LSW helps people gain a sense of control over their life story. This is in contrast to what they usually experience in their independence, medical decisions and environment (Beecham, Anthony and Kurtz 1998).

7.1.3 The benefits of life story work in relation to social network and relationships

A social network is important to being active and engaged, feeling safe and included. The importance of friendships and family to older adults with ID was emphasised in phase one of this study by the 'LSW experts' and in the literature (Thorsen and Hegna Myrvang 2008).

Section 1.1.1 describes the poor social network people with ID in general have. Storytellers in this study also had poor social networks. 74% did not have parents who were still alive and only 31% had family members they visited (siblings, aunts etc.).

Table 5.4 shows that 35% of the storytellers did not have any friends at all - none had a boyfriend or girlfriend (table 5.3).

Results in this study correspond with other surveys which show 40% of those with ID reporting that they had no friends outside the home. The figure for the general population is 2% (Söderström and Tøssebro 2011). 60% report they have a friend among those they live together with (Tøssebro and Lundeby 2002), which is not high considering 94.5 % are 40 years old and more and live in shared flats (Westerberg 2013: see also 2.4). This makes older adults with ID more vulnerable and isolated when someone in their social network dies or moves away (Thorsen 2005).

There may be explanations of why older adults with ID have such poor family networks. One explanation is that their family (up until the late 1970s) were not encouraged to remain in touch with children who lived in HVPU institutions (1.2.1). This resulted in grief and longing on both sides. Some parents felt such a strong sense of guilt and shame that they had difficulty establishing contact with their children again (Knutsen 2006). One example of this was the account of ex-5: *"He is probably autistic', we said. No, he missed his mother, and had been grieving and anxious because he was abandoned at that time. He found her after 25 years and the autistic symptoms disappeared."* No one had tried to find his mother before LSW. Similar stories were told about 'war-children' who were required, in the 1990s and now as adults, to move from the institutions back to the municipality they were born in (2.2.1 & 4.2).

The broken relationships this study shows among older adults with ID represents a particular challenge to staff who work with older adults with ID, in helping them cope with reactions on both sides and encouraging them to build new positive relationships.

Almost every storyteller said they were satisfied with the people around them. This indicates that they generally have a small and good social network. Homes and day centres for older adults with ID give them the best opportunities for making friends. However, only 17-20% of storytellers said they had a friend who they thought was most fond of them (5.3.1). This situation may indicate that they need help to build friendships in their home or in day centres.

The social network is an important source of stories both in LSW and PCA. LSW can also ‘wake up’ social networks. LSW also can be used as a strategy for working with the broken relationships revealed in a storyteller’s life. Susanne Hollund in Denmark has this as a main focus in her LSW model (Hollund 2007b). Storytellers may find that LSW provides them with a golden opportunity to contact family or old friends, as one storyteller did in this study. Her father unfortunately died immediately before she made contact. She however met three half-siblings who became her close family (5.3.2).

The storytellers become, in LSW, more aware of who loves them, including those who were no longer alive. They remembered and talked about old friends and places where they had good times. LSW can in this way ‘awaken’ good feeling about themselves, other people and places.

7.1.3.1 Friendships with staff

Staff are, in general, important to those with ID. Table 5.4 (5.3.1) confirms that staff are at the 'top of the list' of those storytellers like to be with and were most fond of. It was, however, surprising to find that 37% did not know whether they were loved by anyone and only 16% answered that they were loved by a staff member (ibid). This may say something about the service providers (and the Norwegian) reticence to say (and to show) that we care about each other. One reason may be the discussion around friendships between service users and staff in some services. The discussion tends to say that 'it is not professional to have a close friendship with your service user'. This discussion is too extensive and too complex to elaborate here. It would be, however, useful to include this discussion in future research projects.

A positive aspect was that all interlocutors said that they thought the storyteller was an interesting person before LSW. 79% were even more interested in them after the LSW. 'Interest' is an important factor in good conversations and relationships. So is respect. More than half of interlocutors said they had more respect for the storyteller after LSW (6.4.1, see 7.2.1). This may also explain why all interviewees maintained that LSW strengthens the relationship between the service user, the service provider and family members. It seems that a kind of 'symbiosis' develops between the storyteller and their interlocutors during the LSW process. A mutual reinforcement process was activated (see 7.2.2 and table 7.1), which also made the LSW pair feel more comfortable together (6.4.3.1).

It can be concluded that this study confirms that concluded by other researchers, that LSW improves relationships between storytellers and

their staff and thereby ‘benefits both’ (Clarke, Hanson and Ross 2003; McKeown, Clarke and Repper 2006; Woods et al. 2009).

7.1.4 The benefits of life story work related to general satisfaction in life

Satisfaction is strongly related to how we look at our self and our situation in life and often is linked to our personal goals, wishes (2.6.2) and our personality (2.6.1). Empowerment may also be a factor in the assessment of ‘self- satisfaction’. Empowerment may also be an outcome of a process and a ‘mechanism’ that influences people’s opportunities for personal growth.

More storytellers said, after LSW, that their earlier life had been good. One explanation for this may be that they had had more time to remember ‘everything’, not just the most emotional events. Ex-1 said in her interview that those she worked with over a longer period of time started to talk more and more about the good memories; so even a harsh story could start to become more positive (4.2).

Changes in the storytellers’ perception of their residential settings were also evident (5.3.3). It is difficult to say why they more positive after LSW. One explanation may be that this was due to a positive reaction to the extra attention they received from staff and people they lived together with. They were ‘given a role-identity that confirms and justify the value a society gives the person’ (see Wolfensberger 1969, 1972 in 2.2). Their own development may also have had an impact on the people around them in their home, making them more positive. Their communication skills may also have improved, making them more comfortable in a dialogue with other people.

We can generally say that the findings more or less tell the same story - that the storytellers in general are satisfied with their life (their average score were 4.15 in a scale to five). Both the storytellers and their interlocutors scored a little higher on the storytellers satisfaction scale after LSW. However, this increase was not pronounced, even if the 'LSW experts' claim that LSW makes people more satisfied (4.3, 5.3.3 & 6.3.5).

A 'meaningful activity' can be an activity that seems meaningful because it fills the hours or because it has a value in the person's life. An activity that has value is given priority. The enthusiasm, happiness and pride a number of the storytellers expressed in interviews and at closing parties is clear evidence that LSW is a meaningful activity (5.2.2). Literature and other researchers have also concluded that LSW is a meaningful activity (Eidem Krüger 2010; Eriksson 2007; Heathcote 2009; McKee et al. 2003; Van Puyenbroeck and Maes 2009).

7.2 Life story work benefits the interlocutors' professionalism

Professionalism is explored in this study through interlocutor attitudes, knowledge and practice before and after LSW. The positive effect LSW had on interlocutors is discussed below. The section ends with a model that may be seen as a summary of the experiences the interlocutors told about.

7.2.1 The benefits of life story work related to interest and positive attitudes

It was noted in the field reports that interlocutors repeatedly expressed *heartfelt feelings* for their storytellers during the interviews. A degree of emotional engagement with their service users was, obviously, an important part of their job motivation and their motivation for taking part in LSW (see also 7.1.3). They gave much more time and engagement to the LSW than was expected by their employer or the researcher. They explained their use of so much time and their engagement as being due to the lack of resources they faced every day in the service and that they did not want services users to suffer as a result of this. They even worked with LSW for free. In the interviews they talked about how much they wanted to give the storyteller positive experiences with LSW and how much they pushed themselves to do this (6.2).

Some of the interlocutors in this study told that, because of LSW, they did not have time to be sick. They even came to interviews and meetings when they were sick or were not on duty. This level of engagement from the interlocutors raises the question of whether LSW, their close relationship with their service user and a feeling of personal/professional development in their work prevented them from being sick? This assertion was confirmed by the interlocutors (6.5). One (of the few) studies that describes the effects of LSW on staff (nursing home staff and home health aides) concludes with the statement that *"life reviews can impact favorably on staff, with the potential for reducing high rates of personnel turnover…"* (Haber 2006: 166). Turnover was not a topic in this research. However, if this is correct, then it would make a compelling economic argument for implementing LSW in every service in Norway!

The answers the interlocutors gave in the interviews on their interest and motivation for LSW did not correlate well with what most did in practice. Only 26% of the pairs reported that they had carried through the eight week long process without any interruption. The main reasons for this were education courses, national holidays and sick leave of staff (6.2.4). The reason(s) why so few of them achieved a 'continuous a flow' and whether this is a trend in other parts of their work was not explored in this study. The researcher could have found out about this and whether this was more often the case for those carrying out LSW in homes than in day centres. This was however not explored due to the ethical and methodological issues around such information in a small sample. This is an issue that should be considered when LSW is implemented in services. The researcher is unaware of this having been studied before. It however seems to be a relevant consideration in relation to the effectiveness of LSW in a service.

Despite staff absence during LSW, almost every interlocutor said their attitudes had changed in a positive way after LSW. One interesting aspect of their answers was that they were interested in learning more about themselves and their service users (6.4.1).

7.2.2 The benefits of life story work related to the interlocutors practice

It can be questioned whether it is possible for anyone to have a complete and total knowledge about one person? There is, however, no doubt that knowing the service user as much as possible is beneficial to all parties.

One interesting observation was that the respect the interlocutors felt for their storytellers was related to the storyteller's personality and not to their skills or ability (6.4.1). This is also interesting viewed in a historical perspective, people with ID mostly having been described and judged based on their lack of skills and abilities (1.2). This 'personality' aspect (2.6.1) has not been discussed much. The personality perspective makes the work of interlocutors easier. Their role, where this perspective is applied, is to learn what 'type of personality' the service user has, making it also easier to understand how to provide the 'right' support. For example, if the person is an extravert and likes to be spontaneous, sociable and energetic, then support provided through, for example, outdoor group activities should be more frequent than for an introvert who is retiring, quiet, deliberate and withdrawn (2.6.1). Every person is, according to research in neurology and psychology, unique. No two people can be said to be similar, not even twins. Research also shows that these differences are greater when people are old than when they were young (Hooker and McAdams 2003). This tells us that every person who a service provider meets is unique and therefore should be helped in different ways based on their personalities, physical and mental functions and needs. This is what a 'truly' personalised service should aim to achieve.

The answers the storytellers and the interlocutors give when asked about the knowledge staff have on the storyteller differ. 43% of the storytellers said staff had the best knowledge about them. Only 21% of the staff said they knew the storyteller 'very well' (6.4.2). The sample is too small to draw firm conclusions. But it indicates that the service users think the interlocutors have more knowledge about them than the staff think they have.

What does this mean in practice? It suggests that the service users' expectations of what the staff knows about them are high. Staff, on the other hand, may feel under pressure to give advice or support on things they do not have enough information on. It is not always possible in every situation to respond by asking for more information; however, decision making on behalf of another person, based on a low level of knowledge, is fraught with risks and dangers for all parties.

Almost all interlocutors said, after LSW, that their knowledge of the storyteller had changed and, significantly, more than half of them went as far as to say that they had *much more* knowledge about the storyteller than before LSW (6.4.2). Some interlocutors said that they knew the storyteller before LSW from 'top to toe'. They said, after LSW, that their view on important information on the storyteller had changed. They had much more 'new and valuable' knowledge after LSW, e.g. I-12 said: *"… this knowledge is valuable when we talk together. It makes it easier for me to ask, for example, so you were there when you learned that...and things like that."*

On average 75% of the interlocutors said they had more knowledge about the storyteller's 'tolerance limits, interests, values and life cycle' after LSW (table 6.5). The interlocutors said that they had fewer conflicts with the storytellers because they had a greater understanding of the storyteller's behaviour and so felt more comfortable about talking about things (6.4.3.1). This outcome is also found in earlier research e.g.: *"Knowledge of a person's history can provide caregivers with valuable clues about the meaning of words and actions that might at first sight appear meaningless or baffling"* (Bruce and Schweitzer 2008: 168). It is clear that increased knowledge about the service user does provide a basis for more professional practice among the staff.

Older adults with an ID often have a record of poor health and medical treatment. Lack of knowledge about a person's reactions can lead to misjudgements in diagnosis, the course of an illness and, not least, errors in medication (1.2). There are a number of important decisions staff may support the service user in taking in the course of a service user's treatment. Staff may, however, fail to give the correct support if they lack knowledge about the person's medical history, their personal life, tolerance limits and other life events that may have formed their behaviour. LSW is made up of stories told from the service user's perspective. Staff may therefore discover valuable information about the coping strategies the storyteller has used or other actions they have taken to maintain their health (5.3.2 & 6.4.2). LSW can even focus on the person's health, if that is what the storyteller wants to talk about.

It became clear during LSW how important it was for storytellers to have a key worker/proxy who was close to them and who was able to give them good support and advice. A number of interlocutors, who were key workers, said they were afraid of the new trend in services and staff management of the key worker being frequently changed. They were afraid that this could destroy good relationships and the feeling of safety and openness that had been established, which had become even stronger after LSW.

7.2.2.1 The benefits of life story work in relation to older parents

Staff are key people in facilitating the development of new relationships with people who need support and with their families. They are responsible for creating a system that really works for everyone (Newman 2010: 2). Findings in this study show that the interlocutors had some very significant meetings with family members, often involving a level of interaction which had not been experienced before. Most of these interlocutors had worked with the service user for many years (58% > 5 years) (6.1). Their experience of family contacts arising through LSW was therefore all the more surprising. Interlocutors who had met the family and who had meetings with them were not asked about this. A reasonable question to ask them, however, was whether this indicates that LSW had been a good way for them to get to know the family in a different way? Could this also be equally true for the family? If this is 'true' for most interlocutors, then this would suggest that LSW could be an effective tool for building good relations with the service users' family.

This is a further argument for starting LSW when a service user moves into a new home or starts at a new day centre. 'Double ageing' (1.1.1), parents' becoming old and their concern that that will not be able to provide their children with the support they have given them in addition to public services, is also an additional argument. Parents have the most intimate knowledge of their child's life history, development and needs over time. They also know how services have failed in the past. The role of parents in providing continuity is central to the child's life, a relationship that is central to both parties (Thorsen and Hegna Myrvang 2008).

Good contact between service providers and family members is always beneficial for the service user. Good contact can also help family members to feel more secure that the public service will take good care of their child after their death. Staff may also be more professional in PCA because they learn to respect what the parents have done for their child.

7.2.2.2 Professional practice

This study has investigated the effects of LSW on service provider knowledge, attitudes and practice. These can be defined as catchment areas for a professional practice in PCA.

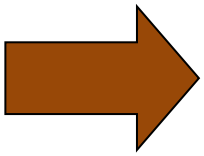
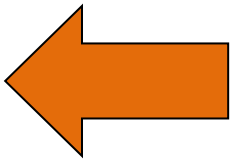
The interlocutors said the role of the 'good listener' in LSW was exciting and motivating even though it could sometimes be, as some said, 'emotionally' hard to listen to the stories (6.2.3). Some learned to be a good listener in LSW and some were surprised about how much the storyteller said or the length of conversations they could have with them (6.4.3). The interlocutors were surprised and impressed about the storytellers' stories, how intelligently they spoke, how much they remembered and how reflective and insightful they were about their past (6.4.2). In other words, some myths or beliefs among the staff were broken or changed during LSW. Some of the interlocutors even felt ashamed because they did not have more time to listen to every service user they worked with (I-3 in 6.5).

The researcher considers that these direct and emotional experiences and reactions among the interlocutors are important for creating a lasting change in the way they undertake PCA. Several staff said they had to start responding more flexibly to what people said was

important to them. This means that the staff education/training must change to be more based on understanding and on reacting to the 'user perspective' (MacNeil and Casey 2010). The specific role in this LSW programme of being supportive but *not* leading or deciding, also resulted in some interlocutors realising that they could beneficially use this approach in their general practice (6.4.3). This is a valuable outcome not only for the interlocutor, but also for service users in general.

The findings in this study show that service users (quite unwittingly) acted as a means of providing personal and professional development to staff. They helped them to become a more professional PCA worker. This 'qualification-flow-model', which I have tried to visualise in table 7.1, has a circular or cyclical effect which is iterative and can draw in others such as family, friends, doctors and therapists to 'learn from the cycle'. It benefits staff and also service users. Descriptions of the 'person with disability' are based on the characteristics of the service users the researcher met in this study. The descriptions will not apply to everyone. This can, however, be a device that can be used to analyse the interactions which (should) take place in LSW or PCA.

Table 7.1: A Person Centred Learning Cycle

from the perspective of a professional	*focus*	*from the perspective of a person with disability*
knowledge: - the system and case handling - people's rights - the policy and laws in the actual field - empirical practice - research in the field they are working - the persons they work with: their life stories, life goals and reactions/traits - communication systems *attitudes:* -the person is viewed as capable of self-understanding with 100% focus on the dialogue/the person's suggestions. Be able to put own needs to one side in a job situation: - kind and good mood - like to be helpful - open - honest - show respect and equality *practice:* -sensitive to others' needs and personality in the practical support - good communication skills - creative - structured - skills to carry out things that are agreed - good at listening and asking the 'right' questions	**be active in listening and observing** **feel equality and respect** **share evaluations**   **be active in listening and observing** **evaluate** **tell stories** **feel trust and liberty**	*knowledge:* - about own situation - how 'you' want to live your life in practice, emotionally and intellectually - about 'your' resources: what am I good at - what do I need help with, what are my ambitions? *attitudes:* -take responsibility for own choices and life - work for the life 'you' want - be open and positive to cooperation with the staff - honest with own feelings *actions:* -communicate own needs and wishes - tell/share stories so people understand who 'you' are (life stories) - do the things 'you' have agreed with others - teach staff, help them to understand and to 'do it right'

7.3 A Norwegian model of life story work

The introduction to this thesis refers to authors in this field who claim that there is a recognised lack of programmes, strategies, evidence-based methods and service models that cover the broad field of ageing and ID (EASPD 2006; Janicki et al. 1999; Janicki, McCallion and Dalton 2000; Watchman 2003; Wilkinson et al. 2004). Section 2.7.2 refers to Danish studies up to 2003 and shows that only one study had a well thought out plan for how LSW should be used on a day-to-day basis and as a tool to provide better services and more individual caring (Moos and Bjorn 2006).

The LSW programme in this study was designed to explore the impact of LSW and to investigate the relevance of LSW in PCA. The positive impact of the LSW programme has led to a section, this section, being included that discusses a 'Norwegian model' of LSW. The discussion focuses on;

- How LSW may be viewed as an approach with possible wider application than older adults with ID
- Important requirements (contexts and mechanisms) in the LSW programme that were developed in this study
- Important issues related to the structure of the programme
- How the LSW programme in general may be a premise for the effective delivery of PCA
- The relation between LSW and IP in PCA

One question in this discussion is how LSW can make a serious contribution to the provision of good care and support for service users in housing and day centres in general and older adults with ID in particular.

Other literature has previously concluded that service users' life stories are a source of information for good planning and for building effective relationships, which form the basis for good support (Cambridge and Carnaby 2005; Pörtner 2000). This study and the Norwegian context provide a fresh look at the service improvement opportunities that can arise from the links between LSW, IP and PCA. The practical suggestions included in this discussion represent a new way of working for staff and may also represent a beneficial supplement to the work already carried out by these services.

Several models of LSW have been reviewed in this study. No single model was, however, found to fit into the Norwegian legal and service system. Current psycho-social theories, models of Norwegian service delivery and national policy and practice guidelines, plus international obligations such as The Convention on the Rights of Persons with Disabilities (UNCPRD), which Norway ratified on 3 June 2013 (Likestillings- og diskrimineringsombudet (LDO) 2013), constitute the present foundation for the LSW programme. It is also recognised that the practising of user-led decisions as a strategy prevents adverse ethical issues, which could represent a threat for participants.

7.3.1 Life story work as a lifelong support to people with disability

> *"If you begin an album, a life story book or the like when you are young, by the time you get old you have such well-founded information that you can look back on and reflect upon, that it will really help you to understand who you are and how you got there" (ex-2).*

McAdams uses theories from, for example, development psychology (2.5.2) to describe peoples' ability to tell a story that begins from when they were children. Information from these theories and

McAdams' contribution are used in this thesis as a basis to describe a 'life cycle perspective' in LSW, as shown in table 7.2.

One reason for considering how LSW may contribute at different life stages is that some respondents in the study said the LSW should have started when the service user was younger and it should be a part of 'everyday life' (4.2 & 6.5). E.g. I-4: *"It should have been a project, which follows them the whole way... not all these medical records, but the other things should be there.... it is so important."*

The 'life cycle model' in table 7.2 is first of all 'an experiment' based on literature on LSW and findings in this study. The 'LSW life cycle perspective' may be a topic for further research/PAR projects. It would be interesting to evaluate the approach and the impact of LSW at different ages and with people of different mental abilities.

Different LSW models have different aims and objectives, depending on what they try to achieve. There is no single universal definition of LSW in the literature (Haber 2006: see also 1.1). The purpose of LSW, when based on a life cycle perspective, is to support the storyteller in their identity and personal development and building relationships with service providers, family and friends. LSW can also convey important information about the person which could improve the support the person subsequently receives.

The table below is based on cognitive/mental development in 'storytelling' for people without ID and is based on a summary of the literature review developed from McAdams et.al. Bearing this in mind, we may assume that people with ID may well tell their stories in a different manner when they are in the age group the model describes. This is also significant for the listener's and the person's identity and personal development. It should be noted that the abilities

of people with ID often are identified more appropriately by the information found in the column headed ‘skills that develop in this period’ than the ‘age group’ column.

Physical impairments alone have less influence on the purpose of LSW. They are more of a practical issue that the participants should solve together. The ‘purposes’ outlined in the final column are not exhaustive, but suggest objectives we may have in LSW that are in addition to practical support with creating albums or other products (2.8.5). The purpose has to be individual, based entirely on the service user’s own wishes or a parent’s or proxy’s if they not are able to express their own LSW purposes.

Table 7.2: A life cycle model in life story work

(mental) age group	**skills that develop in this period**	**purposes of the life story work in a personal development perspective**
0-1	*intentional interaction with others; theory of mind	*stimulate the feeling of safety, confidence and communication ability
2-4	*autobiographical memory – episodic memory becomes personalised *engaged in co-constructing their past experiences *interpretation and understanding their own and others actions	*stimulate the feeling of ‘me’; confidence, communication ability, cooperation and creativity
5-7	*has an understanding of the chronological order, time and place and confirms stories in a conventional story with correct grammar *stories are expected to have a beginning, middle and end, and actions that have consequences	*stimulate the communication ability, use simple text and symbols, cooperation, creativity and the ability to recognise links between own and others feelings and behaviour

8-15	*narrate their own experiences; know how to structure it and what they should include in a good story	*stimulate the communication ability, scholarly skills, cooperation, creativity, fun and confidentiality *support them to: - recognise their own and others' feelings and behaviour - develop a picture of their own skills and possibilities in life e.g. school or work - priorities - telling their stories to their diary or to the 'world'
16-21…	*defining life stories with scenes, settings, characters, plots and themes *explain how different events are linked together and how one event causes, led to, transforms, or meaningfully relates to other events in their life (causal coherence) *traits, attitudes and beliefs may be told and explained by a life story telling *identify a core of life, and identify values, principles or overarching theme (the thematic coherence)	*stimulate the communicative ability, creativity, fun and confidentiality *support them to: - get an overview of their 'origin/roots', and see links between themselves their roots and social heritage - get a picture of own skills and possibilities in life e.g. work and relationships– priorities - telling their stories to their diary or to the 'world'
adulthood	*autobiographical memory and narrative understanding have developed so much that an identity can emerge	*stimulate the creativity, happiness, confidentiality *support them to: - get an overview of their 'origin/roots', and see links between themselves their roots and social heritage - get a picture of their own skills, possibilities and good things in life – priorities - telling their stories to their diary or to the 'world'- generativity and redemptive self; future generations

old age	*continue to refashion their identity and re-narrate their lives in the wake of predictable and unpredictable life changes	*stimulate the creativity, happiness, confidentiality *support them to: - get an overview of their 'origin/roots', and see links between themselves their roots and social heritage - based on own experiences and possibilities, get a picture of the good life in the future– priorities - telling their stories to their diary or to the 'world'- generativity and redemptive self; future generations

The ideas and practice of user led LSW described in the model in table 7.2 will need to be sensitively introduced to the staff and will require sensitive staff training. The service users' must learn how to take responsibility for their own LSW! Some of them will never completely achieve it unaided; physical and cognitive reductions can make them more dependent on help from others to carry out the process successfully (Meininger 2005).

They may also be weakened because they are sick e.g. dementia (1.2). According to Ken Holth, it is better that people do LSW in the early stages of dementia because they are able to choose what they want to share and tell others. We all have stories we do not want to share. Such stories can be difficult to hide and to deal appropriately with when the person has severe cognitive problems (Kaiser 2008).

Some people lack the ability to speak. Some would therefore say they can't 'tell' their story. Staff may use this situation as an argument to conduct LSW without any involvement of the person. The LSW-model in this study is user-led and user-involvement is an absolute requirement.

When another person tells the story with no user input, the story, as told, may not include those self-defining topics that reflect the user's cultural values and norms. It may also include assumptions made by others about how the user's past experiences have shaped their behaviour and reactions.

7.3.2 Important requirements and prerequisites in life story work

It is uncertain whether a LSW precondition should be that service users like to talk about themselves and their life stories. Data analysis showed that half of the storytellers in this study did not like to talk about themselves. But they liked to talk about their past (less about their present and their future; 5.2.1). It is difficult to explain the findings in this study - so many storytellers normally did not like to talk about themselves but were so engaged and happy to be involved with their LSW (ibid). There was no apparent link between the fun they had in doing LSW and their own willingness to talk about themselves. One explanation may be that some storytellers had had painful experiences in the past and they avoided talking about (5.3.2). The system of supervision that was developed in the LSW programme is therefore important (3.7.1), even if it not was used in this study.

All information related to LSW must be accessible to all in text, verbally, drawings, pictures… (3.6.1). Expectations before LSW of participants in this study were high, even if they not had done LSW before (5.2.1 & 6.2.2). The pre-information that prospective participants, family, friends and other service providers received may explain their high levels of motivation. This could also be due to LSW being something new to them.

An important requirement for LSW in this study was that the storyteller and the interlocutor had fun when they took part in LSW. This is based on the researcher's own philosophy that the best learning for all is achieved when we 'play' and laugh. All participants in this study thought LSW had been fun and interesting. The things they thought were 'most fun' are worthy of further consideration and more LSW (5.2 & 6.2). The interlocutors' feeling of doing something important for service users was also important. The things the interlocutors thought were fun and motivating also links to what they think is important in their work.

LSW should be a meaningful activity for service users (and service providers). This means that LSW has a value in the person's life, and in turn that LSW is given priority (see 7.1.4).

7.3.2.1 Participatory action

Service users were included in the development of the LSW programme in this study. They were also included in every information meeting and some played an active role. This 'inclusion', seems to be unusual when comparing this with other LSW programmes. One example is the 'Danish programme' (2.7.2), which begins with a meeting of just the 'interlocutors', who prepare a summary of the person's records (Hollund 2007a). This approach would not have been possible in this research because it would be in conflict with the user-led principle and empowerment theory (2.2 & 3.7.1). Service user's stories told by the staff and told by the person are often different because staff add their own modifications and interpretations (Elliott 2005).

Atkinson discusses this in a study in which people with ID co-constructed their personal and shared histories (Atkinson 2004).

One argument presented in the Danish model is that a meeting with the 'interlocutors' prepares them for meeting the storytellers' reactions (Hollund 2007b). Such 'reactions' were not a problem in this study. No-one had any trouble with storytellers' reactions to the stories they told or visits they made to places during LSW. The agreement on supervision meetings between interlocutors and their managers were never, in fact, used (2.8.2 & 3.7.1). Such problems may also be caused by poor relationships, which was to a great extent avoided in the LSW programme because the storyteller chose their own interlocutor.

7.3.2.2 Interlocutors' prerequisites

There may be situations where the interlocutor needs more pre-information before they start conversations with storytellers. The literature in this thesis indicates that it is important the interlocutor for storytellers with communication difficulties have some knowledge of their personal historical context so they may:

- Understand the behaviour and feelings that people are not able to verbally talk about and that can't be explained by their personality or present life situation, e.g. people who are used to an institutionalised life can react to their environment differently than those who are not used to this
- Have a basis for asking relevant questions in LSW
- Understand the context the storyteller talks about and better understand the importance of it

7.3.2.3 The user-led requirement

The user-led principle and the storyteller's self-determination in the LSW process were essential. Principles of self-advocacy and empowerment are difficult to follow when a 'package' or 'structured questions' approach is used, which often are too close to a professional mapping system (Andersen et al. 2008). In such systems, the storyteller is supposed to follow a system someone else (in this case other professionals) has decided. This may also lead to staff taking over the process, because they have more overview of the 'package' or questions to be answered. The storyteller, in this situation, depends much more on the staff member's initiative and support.

The storyteller was encouraged to do as much as they could to create their own product. The interest shown in the process and in the finished product was, as a result of this, much greater (5.2.3). Some storytellers were uncertain and asked the interlocutor for more help than they needed e.g. to write in the album when they could write themselves. Not every interlocutor managed to support the storyteller sensitively enough and some in this study needed reminding about this when this became clear in the weekly reports. The interlocutors afterwards said that this had been a rich learning experience for them. The variations of the storytellers' products reflected the variation in participants' skills and storytellers' choices.

According to Hussain and Raczka, one of the greatest benefits of LSW is that it adopts a PCA in which the storyteller decides on what to include and exclude (Hussain and Raczka 1997). Talking about things which are of interest to the storyteller encourages them to use their communication skills. The more they communicate,

the more staff respond. This ‘virtuous circle’ (table 7.2) depends on how the staff member views the storyteller. If the staff member is not really engaged in listening, then the storyteller is affected. Staff may then say that the storyteller is not interested.

Another important requirement is that the listeners in LSW must not judge the stories that are told. If the same story is repeated several times, then there is a reason for this! People’s stories must be accepted as they are and as they are told (6.2.6). This requirement was appreciated by all participants in this study. No one reported any problems with this.

7.3.2.4 Aids to remembering, a sheltered place to meet and enough resources

The researcher’s impression was that both the storyteller and the interlocutors had used creative aspects of themselves which they normally were not ‘in contact with’ in day-to-day life and work. Creativity is a human resource in LSW, the creativity to use various sources of information, to make the process interesting and to make a product.

Old photos are important sources that almost every storyteller in this study had (84%). The product, i.e. the album the storytellers made, was ‘memorabilia’ that they could use to tell their story after LSW. During LSW, they used various forms of ‘memorabilia’ to help them remember. They used, for example, old photos, other peoples’ stories and newspapers. This approach is common (Atkinson 1993).

31% of the storytellers told about how hard it was to remember (5.2.4) and interlocutors said it was more challenging to do LSW with storytellers who did not have old pictures. ‘Memorabilia’ is therefore important. Pictures also helped the pair to recognise changes in people, places etc. Pictures may help storytellers to understand and perceive their whole life span up to today, which may change their sense of self-worth and identity.

A difference in age also makes a difference in storytelling. Several older adults had lost family and peers. They may therefore experience their identity and their emotions differently when they tell their stories (McAdams, Josselson and Lieblcih 2001b).

Some old people who are not active or have lived an active life may also need the interlocutor to support them in finding topics to talk about such as in old magazines, travelling to places, museums etc.

Other people are another ‘source of information’ that is important if the storyteller wants to include them. Some of the storytellers included their family, with both positive and not so positive results. Asking those in the storyteller’s social network to take part can awaken ‘old’ relationships, a good enough reason in itself to carry out LSW (4.2).

Other important requirements are having a secluded place to meet and the opportunity to travel and meet other people. Findings in this research show that lack of money was not an issue. But it is important to have enough money to cover, for example, a trip to the storyteller’s childhood home.

7.3.3 The structure in life story work

The process of the LSW programme in this study was quite free. The pair were only expected to have a realistic timetable before starting. The plan was to include an end date for the LSW, and was to be approved by the manager before they started (3.7.2 & 6.2.1). Some of the interlocutors followed the guideline in the LSW book on how to plan a LSW, others did not.

It is suggested in the LSW programme that the pair should meet once a week or more often. It seems that most of the participants had two meetings of one hour a week and they used 8-25 hours to make the product. This indicates a considerable variation. It also indicates that the process and structure were adapted to each person and situation, which is important in LSW. They had a fair amount of time before they actually started the process. They were free to start when they wanted over the period of a month and they had the information they needed and an open line to the supervisor.

The use of an interlocutor from the support service is important in this study. They are first-line staff with various skills, training and formal education (table 6.1). This study analyses the background of the interlocutors as a group. Their methods for tackling the interlocutor role and process were not presented in this study due to lack of reliable data. We do, however, know that the interlocutors were an important element in achieving good results (5.2.2). Some benefits of using first-line staff as interlocutors are:

- Practical considerations such as cost and knowledge of the service: as they are staff they are already paid for the time they are with the service users

- Consideration of the users' confidence: When storytellers select their 'own' interlocutors, using staff from the service means there is a greater chance that they will select someone they feel confident with, who they trust and enjoy talking to
- Makes use of the knowledge and interests of the staff: it is assumed that they have basic relational skills and knowledge about the storyteller and therefore are more relaxed in LSW; even if it is a new task for many of them

7.3.4 Life story work as a serious contribution to the provision of person centred approach

Sections 7.1 and 7.2 discussed LSW in relation to PCA at an individual and relational level[39]. The LSW programme is discussed in this section in relation to the service[40] and in a wider infrastructural psychosocial system that supports or undermines the establishment and duration of LSW. The potential impact on participants is also discussed[41].

Findings in this study suggest LSW could make a serious contribution to the provision of good care and support. It should be a requirement as a first step in PCA because LSW builds relationships and an

[39] Level (i) and (ii) in the 'social reality', see 3.1.2.1

[40] Level (iii) in the 'social reality'

[41] Level (iv)…

understanding of the service user. It also helps collect information as a basis for other individualised services.

LSW can, together with other approaches described in the literature on PCA, strengthen person centred practice e.g. in the 'VIPS-framework' (Brooker 2007). Brooker's itemised descriptions of the importance of asserting the absolute *value* of all human lives (V), of having an *individualised* approach (I), of understanding the *perspective* service users have (P) and emphasising a *social* environment that supports psychological needs (S) are all in harmony with the LSW programme created for this study (ibid).

This study, as well as other research on LSW, confirms the contention that LSW promotes the continued use of such valuable information in everyday care, support and treatment e.g. explanations of behaviour etc. (Meininger 2005; Van Puyenbroeck 2006). LSW is a practical tool to spotlight the unique identity of 'the particular other' through both receiving help and giving help. This is in contrast to the impersonal and 'generalised other' that receive help, which occupies a great deal of evidence-based research and service planning. LSW can be used as a counterpoint to standard procedures in healthcare, as evidenced by LSW being functional, instrumental and focusing on issues and 'diagnostic treatment' (Meininger 2006). LSW may also be more appealing and less threatening than other types of counselling for service users (Haber 2006). The interlocutors in this study also learned that the information provided by the storytellers was often more precise and comprehensive than what they had learned from other staff and from records on service users (6.2.6).

The researcher in this study relied on McAdam's theories and his claims that 'if we lack knowledge about the service user's life story, we cannot say we really know the person' (McAdams 1995). This means that if we only observe a service user's traits and intentions in relation to the behaviour, we lack knowledge about *why* the person 'did it' and the *context* (thoughts, physical environment and other stimuli) that motivated the behaviour. Observation schemas based on direct observation or proxy information should always be supplemented with the person's life stories or there will be many 'missing links'. A conclusion from the literature review is that managing personal services mainly means three things:

- To have *knowledge* about the service user (life, network, personality, etc.), the service (regulations, resources etc.) and an awareness of own resources (knowledge, attitudes and practice)
- To have an *interest* in the person's unique personality and situation
- To have the *abilities* to follow up according to individual preferences and work a 'user participated' and 'individually tailored' care plan

According to MacNeil and Casey *"Personalisation relies on a radical shift in our perspectives of the purpose of the social care system"* (MacNeil and Casey 2010: 103). Professionals, who are used to designing services for service users, must change their perspectives towards being *equal partners* in this process if they want see the people they help achieve a better life (ibid). Sam Newman takes this further and says that there is a need for a *"radical reshaping of the perceptions of those people who need support… The revolution requires us to readjust our perceptions and regard people not as clients and users - but as people who have a right to expect the same as everyone else… paying attention to people's human rights, to*

their right to make mistakes, to live life to the full and to self-determine how life will be" (Newman 2010: 1).

The lack or gap in the research which exists in psychological issues, methods and service models in services for older adults with ID may indicate that the focus on individuality is often less focused on issues such as personalisation and a 'true' PCA than we think.

New literature and studies also confirm the need of a change from a problem-oriented perspective to more focus on the service user's potential. It also confirms the need for a change from focusing on somatic and nursing tasks to a focus on what happens in the meeting between service provider and service user (Ragnarsdóttir 2011; Wallander 2012).

Positive psychology is one of these theories, which also underpins the LSW in this study (2.8.3-4).

The findings in this study show that this 'shift' is possible at a person-to-person level. The LSW programme is a practical tool, easy to conduct and produces outcomes that can be evaluated. Peoples' life stories are, however, just one of a number of approaches we need to make use of in order to realise a 'true' PCA. LSW is, moreover, a 'neutral' approach that is related to all types of realities. This means that everyone in a society carry out LSW in the way they want, with or without help from others.

7.3.4.1 The connection between life story work, individual plan and person centred approach

According to Meininger and van Puyenbroeck and Maes the consequences of LSW in the policy and planning of service systems are unknown. They claim there appears to be no known essential link between LSW and IP (Meininger 2006; Van Puyenbroeck and Maes 2006) The literature review in this study did not uncover findings that prove LSW works as a basis for IP. One of the informants in phase one spoke about this (ex-2 in 6.5.1). Interlocutors however said that LSW is very important and is an important precondition for delivering PCA. They wanted LSW to be a legal right equal to IP (6.5.1). I think if LSW does become a legal right, then their freedom to decline participation in LSW also should be included in the law.

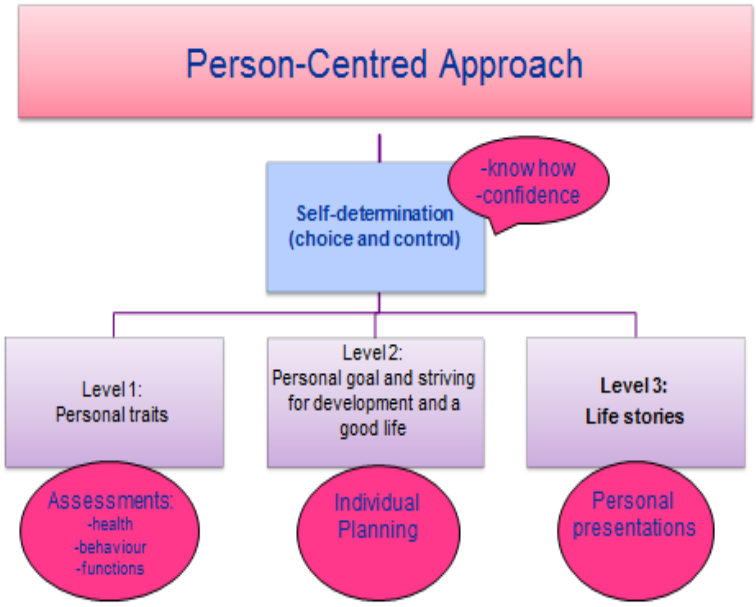
It is interesting, bearing in mind the low frequency of IP in Norway (2.3), that about 2/3 of the storytellers did not like to talk about their future (5.2.1). Individual planning is probably not the most motivating topic to them, even though it might affect them. One of the oldest storytellers (79 years old) said: *"(laughs)…I don't care about that."* (S-19/pre).

Despite these findings, the researcher's impression is that most of the storytellers *had* talked about their future in the LSW meetings and some of them had even included plans in their album (5.2.3). The findings relating to the lack of interlocutors stability in the LSW process over time could be a general problem in most services and could be one of a number of explanations behind the lack of IP's in Norwegian services?

The PCA model in figure 7.1 in this thesis is based on central theories, strategies and knowledge inspired by McAdams' life story model of identity (table 2.3). The use of McAdams' model may influence arguments and the basis for LSW as an approach in services for older adults with ID. His personality constructs a model/ life story model of identity and creates a basis for an understanding of individual differences and similarities. This is useful in understanding how we can get to know people's personal characteristics. The levels model, defined by McAdams, shows the link between traits, characteristic adaptations and life stories. This can be used to analyse the level of knowledge of the service providers who practise PCA in contemporary services for older adults with ID. The model may also be used to identify the whole spectrum of the PCA.

Figure 7.1 shows the relationships between assessments, individual planning, individual presentations and contemporary ideology/strategies related to the service user's right to decide in their life and having enough knowledge to do so. The model emphasises the personality aspect, which can be used as an analytical tool for services. The provision of good care and support by a service can be analysed from a personality perspective. For example, a service that does not use IP and does not conduct LSW will reduce the service users' ability to demand their legal rights met. Services that only focus on people's traits use 'conventional' assessment tools to obtain information about the person's health and behaviour. This approach is embedded in the service provider's own professional area of expertise. A service user often therefore does not have the knowledge needed to be an active and reflective partner. There are, however, laws about informed consent.

Figure 7.1: A personality constructs model for person centred approach



7.4 From theories of disability and life story work - into political changes in Norwegian services

The literature review, the findings in this study and discussions in previous sections form the basis for the discussion in this thesis of current explanatory theories of disability and other recognised theories related to LSW. This thesis considers the arguments for making policy changes based on these research findings and the current legal framework in Norway and human rights considerations arising from the UNCRPD.

7.4.1 A discussion of disability based on psychological theories relevant to the life story work in this thesis

It is reported at a number of points in this thesis that there is a lack of literature on the personal perspective, older adults with ID and PCA. It is also clear that there is a lack of knowledge about the personality as the 'driving force' in discussions about 'optimal ageing'(Hooker and McAdams 2003).

Studies based on positive psychology and optimal ageing in a life cycle perspective may focus on peoples' coping strategies (as revealed in personal life stories) rather than on their disability. A person's recognition of their coping strategies and the coping strategies of those in the same life situation is one way of taking responsibility for their life and their personal learning about life. This approach could have been relevant in services for older adults with ID. There is, however, a need for research projects that explore how this can be done to achieve the best possible outcomes for service users.

'Identity' is peoples' self-defined life stories' (McAdams 2001), which may explain the identity development the storytellers in this study experienced after their LSW. McAdams bases his theories on research involving people without ID. It is, however, evident in this thesis that some of his theories are also relevant to people with ID. For example, some of the interlocutors said after LSW that the storytellers' identity appeared to be clearer (22%) and that the person appeared to have a stronger personality (71%). The storytellers were more self-secure, more communicative and open, they took more initiative, they were clearer and stronger in their opinions and they had an improved self-image (6.3.5). It is evident that these changes could not have been triggered by other events.

McAdam's theory is probably not supported by other professionals in this field. They say that ordinary psychological theories about identity cannot be applied to the understanding of identity development in people with ID. This is mainly because of the unusual life experiences they have had due to their disability (Baron, Riddell and Wilson 1999; Svendsen 2004; Svendsen 2012). It is, however, interesting to note that about half of the storytellers said they had become the person they are because of their disability (5.4). This means that there can be no firm conclusion as to what extent and in what ways they believe their own disability has affected their identity and life in general.

Another example of identity from this study is 3/4 of the storytellers answering 'me' or their first name when asked the question 'who are you'. Some of them elaborated and told about emotions and the skills and jobs they have or have had. The answers the storytellers gave seem to be not so different from the kind of answers we would expect from people without an ID. There are, however, other differences in the things they talked about, such as where they worked, day centre or sheltered workplaces for people with disability. This indicates that some of the storytellers' feelings and thoughts about 'who' they were may be influenced by factors in the environment e.g. an 'unusual' workplace. Does this mean that the general construction of their identity differs from that of other people? Or that their identity can be said to be different from the identity of others? Findings in this thesis suggest that their identity construct is similar to others. They just have individual life stories - like everybody else (2.6.3).

There are differences between some of their traits and those of people without ID. This is because most have syndromes related to their brain damage. Their life goals and interests may be similar to those of the people they live with, and to those elsewhere in society (2.6.2).

None of the storytellers' in this study have lived an independent life, fully included in society (1.2.1 & 5.1). This will be the same for the coming generations of people with ID who are growing up in Norway today (Tidemand-Andersen 2010). If they had been 'fellow citizens' in schools and ordinary workplaces, then their situation and options in life may also have been different.

It is interesting to note that about half of the storytellers said they were a normal person and not an abnormal person. A similar theme emerged from the results relating to how similar or different they felt they were to people without ID. The results that relate to how much and in what way they said that their disability affected their life and the perceptions they have about themselves are therefore not clear. The limited sample makes it difficult to draw a clear conclusion. The results are perhaps more relevant as a basis for reflecting upon what older adults with ID think about their lives and themselves. The questions used in this thesis could, however, be used in a further research project. Such a project should use a bigger group of people to be able to draw clearer conclusions about how people with ID at every age, perceive themselves. Some researchers have already studied this question, for example Brown et al.; *"I am a normal man': a narrative analysis of the accounts of older people with Down's syndrome who lived in institutionalised settings."* (Brown, Dodd and Vetere 2010). A study that uses a larger sample would probably give more answers on the construction and development of the identity of people with ID.

The interlocutors found, after LSW, that they had at their disposal a larger number of ways to help the storyteller's personal development. The interlocutors had more knowledge about the storyteller's tolerance limits, interests, values and life cycle (table 6.5).

We may assume they also had more knowledge about the storyteller's emotions, their aspirations and personality.

Knowledge about where and why a person's values and emotions have been formed, constitute another layer of understanding of the person's behaviour, interests and life goals. Using this greater understanding might make it easier to obtain a clearer idea of what the storyteller is able to do and the changes they can make in their lives.

The greater understanding of the interlocutors changed their attitudes, their knowledge and practice. This, over time, may in turn strengthen the storytellers' feeling of 'who' they are, what they are able to do, their options and their possibilities, as shown in the *Person Centred Learning Cycle* (table 7.1).

Some professionals claim that the challenges in an interaction between people without and with ID are at the 'interpersonal' plane more than the cognitive, behavioural and skill-related levels. This prevents the development of a feeling of 'us' or 'we' in a dialogue (Lorentzen 2006). However, some of the interlocutors in this study said that when they talked with the storyteller about life experiences, they identified as an equal human being and with similar experiences and feelings around these experiences. They experienced a feeling of 'we' and 'us' when they talked together. These mutual confirmations of each other's life experiences may also help to build self-confidence, pride and interest in each other. Indeed, 76% of the interlocutors said they were even more interested in the storyteller after LSW (6.4.1).

7.4.2 A discussion of central elements in life story work related to some explanatory theories of disability and political actions

> *"Using scientifically based models and methods is a powerful way of figuring out the generality of psychological laws and of individual and cultural beliefs, and the significance of historical events." (Tyler 2001: 26).*

Some researchers are critical of the Western models of disability and claim the models are too focused on physical realities rather than on mental representations of these realities. The critics say that social models have not adequately taken into account the differences contained in contextual, socio cultural and individual differences (Hickey 2006; Tyler 2001). Hickey claims that social models should be conceptualised and expressed in ways that accommodate difference and diversity. Ways that involve the creation of more, rather than fewer, options (Hickey 2006). He suggests models that have the potential to challenge existing myths about impairment and that remove at least some of the barriers that currently prevent people from participating fully in 'their communities': *"the negative concept of disability should be replaced by a positive concept of equal access for all, whatever their differing abilities are"* (Hickey 2006: 38).

7.4.2.1 Declining myths

The relational model, which has grown out of the critiques of the social model, is more widely used in Scandinavia than in the English speaking world (Shakespeare 2004; Watson 2001). Both the social model and the Scandinavian relational model assume that people with a disability define themselves as disabled.

Only about half (47%) of the storytellers in this study said they were disabled (5.4). The researcher did not ask about their experience with social barriers and discrimination. However an average of 75.5% responded that they were the person they are because of their job, experiences, music and the people who loved them. Again these are more general answers, ones that are not related to their view of their disability. The findings indicate that not every person with a disability thinks the disability is the major factor in their life. It may also indicate that people have a great ability to fit into and to accept the life situation which society 'provides'. It seems that they have adapted to their situation without asking questions about their rights or whether they are treated equally compared to other people. Maybe there are people with disability who do not really consider their disability. They are just 'me' and they are satisfied with that (5.3.3 & 5.4). Such findings run counter to claims that people with ID recognise their disability as a major factor in their life (Mason 2000). The results of this study tell us that it is a myth that every older adult with ID:

- Feels insecure about new situations and new tasks
- Is influenced by their painful past and so feels less confident because of this
- Likes to relax most of the time

Over 3/4 of the storytellers in the study said they like surprises. Almost 90% like to travel and over half the group liked to be active and to have many things to do every day (5.4). These results tell us that there is a gap between 'who' the older adults say they are, what they like doing and the kind of services some interlocutors said that they received from the local authority. Some interlocutors reported that the resources available to services for older adults have been

reduced to such an extent that if one resident in a house did not want to go on a group activity, then the trip had to be cancelled (6.5).

7.4.2.2 Gaps between ideals and practice

The social model emphasises people's ability to discuss their life stories openly and view this as essential for the influences, knowledge and concern society should have for the situation of people with disabilities *"… 'who we are' (are prevented from being), and how we feel and think about ourselves."* (Thomas 1999: 46). This cannot be said to be a trend in Norway today. There are, however, a few exceptions (see 7.5).

There has been a development in services for people with ID in Norway and other countries. The focus on integration, ADL[42] and social training has moved on to a focus, today, on how to ensure that service users are supported in their endeavours to achieve their goals and aspirations (APS Group Scotland 2013; NAKU 2012). The current focus is on a larger view of personal development. Services users are, in this, encouraged and enabled to be aware of their own personal goals and aspirations, to speak up for themselves and have clear ideas about what they want.

[42] Activity of Daily Living

The change from being controlled by staff and services to being considered as having clear ideas about their own life goals, has been remarkably quick (1.2). Interlocutors who said that the personal and identity development of older adults with ID was a new idea to them and that their day-to-day focus was more on providing services to cover the practical needs of service users (6.3.1 & 6.3.5), actually said something about the gap between political objectives and practice.

7.4.2.3 Life story work versus user surveys

There is a tendency in the self-advocacy movement for 'self-advocacy' to be used as a strategy in services for working with user interaction e.g. user-surveys. These strategies do not challenge the basic oppression systems which exclude and discriminate people with disabilities. It is unknown to what extent service users with ID are involved in the evaluation of the services they receive. Norwegian law stipulates that they have the right to be heard and to be asked about their experiences (Helse- og omsorgsdepartementet 1999). It is also unknown how many have had the opportunity to comment on the qualifications their service providers should have.

There is a clear difference between LSW and user-surveys. LSW is not a measurement or a survey of 'something' which professionals or other parts of society want to know more about. The storyteller has the power in LSW, as only they know the stories and only they can tell them. It is not based on what staff or society says about them or other topics they are asked to talk about.

This study was not primarily concerned with how representative this group was of people with an ID. Some of the experiences they talked about may well have relevance to others. For example, the living conditions in the old HVPU institutions.

7.4.2.4 The risks of paternalism

The way LSW is planned in this study could represent a re-definition of the 'independence concept' described by the social model (Oliver 1996c: see also 7.4). This is because the storytellers are viewed as autonomous in the management of the LSW process. The interlocutor's role has similarities with the 'advisor role' in self-advocacy organisations. They act as a motivator, catalyst and resource person who believe and trust in the person's ability and provide opportunities for them to feel confident (Askheim 2008; Goodley 2000; Simons 1992).

Goodley claims that an advisor's role challenges the authority a professional has as the 'I know best' person. The risk of an advisor adopting paternalistic and authoritarian attitudes is so great that an 'advisor's role' should be avoided altogether (Goodley 1997). This means that the close relationship between the storyteller and the interlocutor that is encouraged in this study, is in direct conflict with the social model's idea of a need for an effective 'defence of the user against the service and the service provider'. 'Professional power' is understood, in this model, to be a form of oppression of the service user (Askheim 2008; Pedlar and Hutchison 2000).

The intention of this study was to make storytellers *feel comfortable*, and to make them feel they had control right from the start of LSW as this could give them the opportunity to feel equality with the interlocutors; *"Power given by a worker leaves the power with the worker. Clients must take power, and it is the role of social worker to organise the institutional response which makes this possible."* (Payne 1997: 284).

This study indicates that the interlocutors were not aware of how important they were to their service users. Almost all were prepared to oppose their employer to defend their user's rights and over half of the group had already done this (6.4.1).

7.4.2.5 Preventing social discrimination

LSW may be used to prevent social discrimination and the building of 'barriers'. Telling their life stories may help people to be more aware of the life they live. It must, however, be accepted that not every person with a disability is interested or able to undertake such a 'struggle'.

The Scandinavian relational model is linked to Norwegian politics, education and service development. There is a strong link in Norway between political and economic issues, between government and user-organisations and governmental engagement and redistributive perspectives. These links may explain why there are so few 'struggles' against oppression in Norway (Askheim 2008; Grue 2004).

Table 7.1 describes the *Person Centred Learning Cycle* that the researcher in this study believes is created when interlocutor and the storyteller perceive the same information about a task they are to carry

out together, e.g. LSW. This process is more challenging when the storyteller has a severe disability. Some of the storytellers in this study had disabilities that were severe. If staff are very busy, service users may be expected to wait until the staff member has time. The service user is then 'placed' in a receiver role. If the service user does not want to 'receive' the service when the staff happen to have the time, then it is the service user who has a problem! Those who protest are at risk of being characterised as ungrateful or of being labelled with a psycho-medical diagnosis.

This issue often prompts the questions 'who is the owner of the problem?', 'what the interplay is' and 'what can be done by whom?' (Askheim 2008; Goble 2004; Harris 1995; Ryan and Thomas 1987; Swain et al. 2004). According to Goodley, such expectations are *"…really the major methods of control in any kind of culture or community"* (Goodwin 1991: 57). This issue was also reported by the participants in interviews and in weekly reports in this study. They also said that LSW was a counterbalance against the interlocutors' lack of time to talk with the storyteller (6.2.3 & 6.2.5).

7.4.2.6 Demonstrating human rights

The results of this study indicate that both service users and service providers lack knowledge and practice within general human rights and the rights given to service users by Norwegian law in particular. This means that the local public service system needs to strengthen their understanding and use of the legal, political and practical aspects of personalisation in the services they provide or purchase.

Norwegian policy and service development is inclined towards more personalised services. It must, however, be admitted that Norway cannot be said to be a leading country in the delivery of services using PCA.

There are results in this study which support the idea of LSW being a basis for delivering a more personalised approach. Good knowledge about the service user is an absolute requirement in PCA. How much knowledge is needed is another question which is explored in this study. The short answer to this is that it must, at the very least, include the person's life story.

Questions about disability, social valorisation and empowerment theories have to be considered in relation to the issue of human rights**.** LSW is one approach that Norwegian services can use to demonstrate that they are delivering on the commitments of the Convention on the Rights of Persons with Disabilities (UNCPRD) (Likestillings- og diskrimineringsombudet (LDO) 2013; see also sections 2.2.1 and 6.4.9). The principles and requirements stipulated by the UNCPRD are also reflected in the design and delivery of this study's LSW programme. The study's LSW programme has, by any benchmark, demonstrated a positive impact upon storytellers and their interlocutors.

The last part of this discussion section is a reflexive account of the research process and the position and role I have had in this (Oliver 2008).

7.5 Reflections on the research process, the role and position of the researcher

Much has been said in this thesis about research philosophy, design, methods and the importance of the participatory approach. They are fundamental to my study and engagement in this field. My practical involvement in the research was also an important element to keep in mind all the way through the study.

This doctorate, which has taken seven years to complete, has always been interesting and engaging. There have, however, been a number of interruptions in this work. Some have been of my own choice; others have been periods of sickness and when other work has taken priority.

My interest in LSW started in the early of 80s when I undertook a first degree in health and social education. In one of the practice periods, I met a woman with dementia who was very afraid of the shared bathroom at her nursing home. I was a student at that time and so, perhaps naively, I started to talk to her and found out that we had much in common. We had lived in the same place in Oslo. When she told me this, I understood why she did not like to shower. She was not used to it. She had rarely showered before she, because of dementia, came to the nursing home. Staff were informed and they decided that she could be helped to wash herself in the sink that was in her room. She, as a result of this, stopped sitting outside the bathroom and was more relaxed. She said that all her family had died, so I ‘adopted’ her as a temporary friend for as long as she was at the nursing home. I did not know at that time that I was doing LSW.

But I have never forgotten her reactions and how easy it was to change the problem she and the staff had. There have been other similar episodes in my working life that have prompted me to study the practices which have been described here as LSW in greater depth.

Before I started with this PhD at the University of Edinburgh, I was working in a Norwegian national program related to older adults with ID. This was why 'they' were the first choice of participants for this research. However, they were also chosen because my employer supported this study. One more pragmatic reason was that I had a wide professional network, which I consulted on the idea of studying LSW. Everyone consulted said that they thought the topic was interesting and relevant to their service users and to services in general. A number of 'gatekeepers' contacted me and said they were ready to start almost before I had submitted my application to the University.

One of the first things I did when I started at the University was to enrol onto all the English courses provided for foreign students. I, at the same time, started research courses and every other course that was available. My English was not my strongest point and, looking back, the language barrier has been the hardest hurdle to overcome. Part of my motivation for studying at the University of Edinburgh was to improve my English. Every step in this research process has been taken because I wanted to learn and the learning process has been the most important motivation for continuing my research for all these years.

In the first phase approval, one examiner suggested McAdams literature as relevant to this study. I therefore started a new review about identity, this time with better outcomes and a better understanding of personality and identity development than the first. Based on this, and more reviews of LSW, an interview guide for 'LSW experts' was developed and piloted with an experienced English author in this field. Minor revisions were made before it was translated into Norwegian. The translation was checked by another professional. I understood around this time that translation and checking translations would be one of the hardest aspects of this thesis.

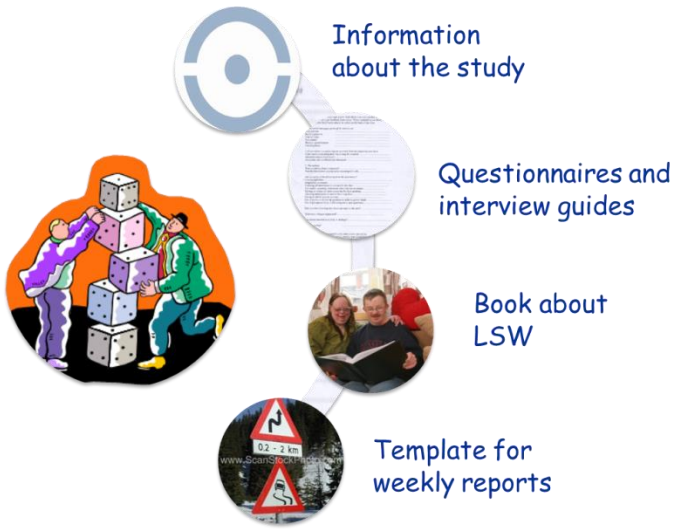
My international network was a great benefit and made it possible to find six 'LSW experts' from three different countries. The first interview was in Scotland. It was a long journey to meet this expert, but it really was worth it. It was an interview I always will remember, with laughter and tears. This was a good start to a series of really good interviews with six 'LSW experts' in English, Danish and Norwegian. One concern was the time the interviews took. I knew that I had to transcribe it all and send it back to the interviewee for comments and checking before they were translated. All interviewees approved the transcripts and the interviews were analysed and described in a new research proposal for phase two. I, at this time started, to use NVivo to transcribe. This was a very useful tool for later research processes.

Phase two was approved by the University after some corrections. I had planned using, in phase two, a flexible design and triangulation of the data collection. The University advised me to conduct semi-structured interviews with *all* participants, not just some of them.

I was positive to this, even though I knew that it would produce a huge amount of transcription and translation. The most important thing for me was the approval I obtained to develop research instruments in phase two with some participants. This was important to me and I looked forward to this process. There was not much literature on similar projects, so I used earlier experiences, creativity and my professional network to guide me.

The process of developing the research instruments was effective and the final result required very few corrections after the pilots. The process and results of the process was evident (3.6.1).

Figure 7.2: Research tools in accessible text as a result of phase one



Then I started phase two. The first meetings with participants were exciting. At some centres there were big meetings with speeches about LSW and related themes. In others there were just small meetings with prospective participants. I have many years' experience as a teacher.

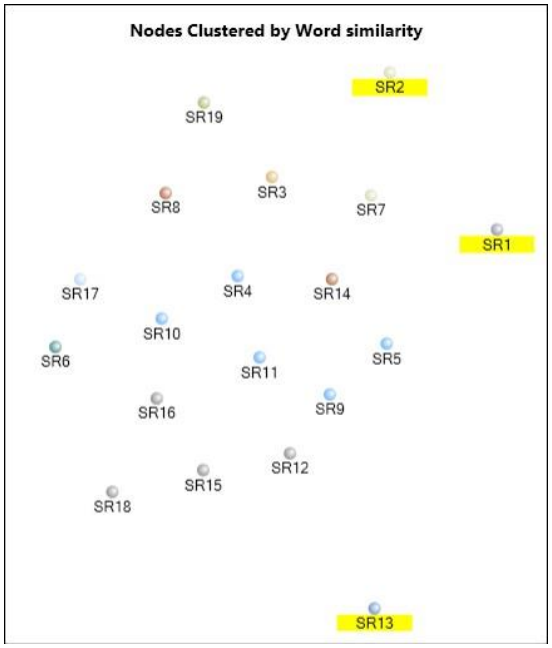
So I gave the centres that participated in the research programme free advice and support. Every centre wanted this, so I ran one day courses on a number of topics for each of them. This was a good way to gain more knowledge about the centres I would be working with which would, later, give me a better understanding of what the participants talked about in their interviews.

At the first meeting, staff or the family of the prospective storytellers supported them in completing the consent declaration and the pre-questionnaire. Every participant in this study filled out a pre-questionnaire, which provided useful information to the researcher in data collection and later in the analysis. Ethical issues were reviewed and there were no difficulties conducting the plans. One explanation for this may be that I know this field so well.

The first interviews were piloted and small corrections were made to the interview guide before the next interviews. The first interview I had with a storyteller was as special as the first interview with the ‘LSW expert’. The storyteller answered that he was an 'idiot' when he was asked who he was. I was stunned because his answer came so unexpectedly. But this storyteller was not the only one that surprised me. I discovered something new and that I had never had heard of before in every interview with storytellers. I had expected the storytellers to have given answers that were more similar than they did. As the scatterplot in ‘figure 7.3: Clustered by Word similarity’, shows, they are clustered but not really similar.

There are some small deviations with ‘S-1’[43], ‘S-2’ and S-13, which may be explained by the fact that S-1 and S-2 were in the pilot and S-13 dropped out after a while.

Figure 7.3 Nodes Clustered by Word similarity



The interviews with the interlocutors were also very interesting. I was impressed over how concerned they were for their service users. The storytellers had chosen some very good interlocutors. Those who seemed to be rather quiet and who had not had so much to say at the beginning of the interview turned out to be the most interesting. Over time, I got to know some of these interlocutors as very interesting service providers with exciting ideas and very professional views.

[43] ‘SR’ is equal to ‘S’

The insider perspective I had in this study, viewing the knowledge of the participant as paramount in both understanding the LSW programme and making it work, was not especially challenging. I believe this is because the design and research strategies and the instruments worked so well. Data collection worked systematically with good control of the process and of variables that could influence results e.g. interpretation of answers.

The field reports were important to reflective practice in the interviews and to improve the interview situation. The reports were also useful in data analysis. Transcription and translation of 79 interviews was a major task. I translated and transcribed everything, with the use of NVivo for the first time in my life - because I wanted to learn the system. I have followed the same model in both phases, even if there were some differences in the use of the NVivo.

The participants in this study had 'relevance' in that their characteristics fit into the purpose for the study. Their contributions have been invaluable. They have given me their experience and managers have used their professional knowledge and role to make the LSW project possible. The storytellers in particular have given this study more value than the researcher ever thought was possible.

The purpose of this research has remained the same all the way through. The aims and research questions in this thesis have, however, been difficult. Not because the purpose of the study or main objectives have been unclear to me, but because of the cultural differences in writing about them between Norway and Scotland. The English language has been a major factor in why this has been so challenging.

The study started with discussions on practice and has ended with discussions on practice through the books the researcher has written about LSW over the last years. These books do not discuss the results of this research. They do, however, lay the basis for further work in this field in Norway. The next step is to develop the LSW book that will be produced from this research and to arrange courses in LSW, based on the LSW programme. Several of the suggestions that were mentioned in different discussions in this section also provide inspiration for future research projects. It has been important to me that I carried out this research together with people with disability. It is equally important to me to make my research results accessible to people with ID. These are the two main objectives of my future work in this field. I have avoided writing too much in this reflective part on issues and topics that have been discussed earlier in this thesis. We therefore now move directly to the conclusions.

8 Conclusion

This study included 44 participants. Six were experienced life story workers, teachers and supporters in LSW and 19 were service providers from day centres and homes where the 19 participants with ID lived. The participants with ID were a group of 14 women and 5 men, aged from 49 to 78 years, with an average age of 63.

Data was collected from 44 pre-questionnaires and 79 interviews. Interviews were conducted with the same person twice, before and after LSW (36 interlocutors[44] and 37 storytellers). The participants delivered 148 weekly reports during their LSW. 15 film clips, 89 pictures and 82 field reports were also analysed with the data mentioned above (table 3.1).

The six 'LSW experts' consisted of three men and three women. They had been working on average for 22.5 years with people with ID and on average 16.8 years with LSW. The service providers that the storytellers chose to be their interlocutors had on average worked with the storyteller for 7.8 years. 42% had known the storyteller for more than 10 years. 68% of the interlocutors had one year of post-school formal training and 37% had bachelor degrees. 57% of these were social educators.

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[44] One pair did not complete their LSW, but a post-interview was conducted with them together.

A significant outcome of this thesis has been the successful development of research tools with the participants. Tools with accessible text and the interviews with people with ID. The interview experience should encourage every researcher in this field to cooperate and include people with ID in their research. Another success has been the LSW programme that was developed. This work was fundamental to this thesis and the book will be published in accessible text and include the results from this study (in the autumn of 2016 by Universitetsforlaget). The participatory approach was a success, which indicates that the methodology related to this thesis worked well.

Limitations to be taken into account when planning future research are the relative dearth of data and therefore the lack of a discussion on the life cycle perspectives of LSW in relation to people with ID. This is an important topic in the context of promoting a person centred approach to people with ID in every age. A number of projects in the literature reviews in this thesis, in which LSW has been used with small children and with people in palliative care, have been analysed. It might have been useful, based on these reviews, to run an extended analysis of the findings on identity and personal development and relate this to a discussion of the life cycle perspective, with a focus on life transmissions. This was not possible because of time and regulations on the maximum number of words permitted in this thesis.

Another limitation, as mentioned in 7.7.3, is that the number of interviewees in this study makes it difficult to find conclusive evidence on some of the themes that emerge in some of the results. One example is finding out more about why the interlocutors planned for holidays and courses when they knew the project lasted for only eight weeks (6.2.4).

What was their motivation for not waiting until the process was finished? This is all the more surprising because they said they enjoyed the LSW so much.

Other limitations to be taken into consideration when planning future research limitation, is that the impact of LSW on the staff in general was not explored. Storytellers were asked whether they had experienced any positive changes in the staff in general. Some (28%) said the staff in general had changed a 'little bit', but this finding is not evident.

There have been a number of less important limitations in this study. These are mentioned in the text. One limitation, which is the amount of time this research project has taken, is important to further, international research projects. The amount of time translation has taken, combined with the researcher's situation as a non-native English speaker, has been challenging and resulted in a much lengthier research process than might have been expected.

The principal aim of this research was to develop and apply a model to promote LSW as a service in Norway. To enable this, two secondary aims led the research process:

1) To evidence the impact of life story work on participants
2) To explore the contribution of life story work in the delivering of a person centred approach for older adults with intellectual disabilities in Norway

The above aims have been achieved by providing evidence relating to the following objectives:

a. To explore LSW among experienced professionals in LSW in Norway and two other countries where LSW is frequently used, to

create a basis for a participatory action research of a LSW programme developed in this research

b. To engage the participants in developing and evaluating a LSW programme that seems suitable for Norwegian services
    - Researching and analysing relevant literature on a number of international LSW models and their usefulness in Norwegian services
c. To evidence the benefits/impact of LSW in older adults with ID and their interlocutors by
    - Analysing the process and outcomes LSW had for the storytellers' identity, their personal development and their interlocutors' professionalism
    - Analysing the participants' experiences with LSW in this study and their perception of the importance of LSW in the services

The result of the first research aim is that it is evident that the LSW programme in this study was beneficial to older adults with ID, the storytellers. The LSW programme had a particular effect on:

- Their identity development; their identity appeared to be clearer and they were more self-assured, more communicative and open, they took more initiative, they were clearer and stronger in their opinions and they had an improved self-image
- Their personal development; the person appeared to have a stronger personality, they felt more enthusiastic, proud and happy
- Their empowerment; they felt more important, powerful and they became more aware of their opportunities to decide things
- Their social network and social skills, especially the service providers contact with their family
- The respect the interlocutors' (and others) had for them

- The interlocutor’s (and other's) understanding of their personality, their behaviour and the importance of the stories they told about
- The interlocutors’ feelings of commitment and loyalty to them increased, which resulted in them defending the storytellers interests and reputation in staff meetings and in general services

The result of the first aim shows that the LSW programme in this study was beneficial to the service providers (who were chosen by the storyteller to be interlocutor) in day centres and in homes. The LSW programme had a particular effect on:

- It created an increased interest in the storytellers in general and especially in their personality and life stories
- They were more interested to learn about themselves and found their attitudes had become more positive, based on a respect for the storyteller’s personality (and not necessarily their skills or ability)
- It increased the feeling of equality, their understanding of the storytellers reactions and emotions in daily life improved
- They had more ideas about how they could support older storytellers in maintaining and developing identity and personal abilities
- They think they have improved their person centred approach in the care and treatment of older adults with ID. Their ability to work in a more person centred way increased because they have a greater focus on the storyteller’s personality i.e. extrovert or introvert

- They had increased knowledge about the storyteller's 'tolerance limits, interests, values and life cycle', which made them more professional in their person centred practice
- They had improved their skills around being a good listener
- They realised that, as a result of their specific role in this LSW programme being a supportive role but not a leading or deciding role, that they could beneficially use this approach in their general practice

This study indicates that the interlocutors were not aware of how important they were to their service users. On the other hand, almost everybody was ready to oppose their employer to defend their user's rights.

For both parties there is evidence that:

- Both service users and service providers lack knowledge and practice in human rights in general and the rights a service user has according to Norwegian law in particular
- In this research, a clear effect has been the possibility/opportunity to build relationships between service user and service provider and the effect on those relationship themselves

The possible innovative contribution of this research is

i) The participatory approach that is used in this study can be transferred to other fields, for example to the Norwegian municipalities, to help develop better information about service users' rights and other issues related to their living conditions.

ii) The life story work programme, as it appears today, constitutes a summary of various theories that have been

used in a new way to provide an original contribution to knowledge in LSW and person centred services related to older adults with ID and their service provider. It can additionally be used with and possibly improve the effect of mapping and planning systems which Norwegian services use currently

iii) It is clear that the personal construct theory/life story identity theory from the American psychologist/professor Dan P. McAdams may also be beneficially used as a theoretical fundament for person centred services to understand identity and personal development among older adults with ID

iv) Finally, life story work is one approach which Norwegian services could use to demonstrate that they are delivering on the commitments that arise from the Convention on the Rights of Persons with Disabilities (UNCPRD)

I will end this thesis with a statement from a weekly report that I think most clearly says what life story work means to the people who are doing it - which is the most important aspect:

"…life story work is a unique way to get to know old history and for the storytellers to have the opportunity to come out with their own experiences and tell others what they have done and what they want to do in the future. It is a unique opportunity for staff in the many residences to give the users' time to understand why things are the way they are, and it is a fantastic opportunity to get to know each other better, and enjoy ourselves…. We both have enjoyed this project immensely." (P-2/WR)

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Appendices

v/Britt-Evy Westergård

8 220 words/40 pages

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Appendix 1: Information, Consent statement and pre-questionnaire for experienced service providers in life story work – letter in advance.

- PRESENTATION OF THE RESEARCH PROJECT,
- SUBJECTS OF THE INTERVIEW,
- INFORMED CONSENT FORM,
- PERSONAL DETAILS AND
- EXPERIENCE

Presentasjon of the research project

Research project title: *Life story work - a new approach to the person centred supporting of older adults with an intellectual disability in Norway? - A qualitative evaluation of the impact from life story work on storytellers and their interlocutors*

Researcher Name: *Britt-Evy Westergård, PhD student at Department of Social work, University of Edinburgh and employed at Norwegian National Advisory Unit on Ageing and Health. E-mail:bew@aldringoghelse.no. Mob UK: 075 925 66 400/Norway:+47 993 56 380.*

Funders for the research project are Norwegian National Advisory Unit on Ageing and Health and Research Council in South-Eastern Norway, Regional Health Authority. Supervisors from the University of Edinburgh are Dr. Heather Wilkinson and Susan Hunter.

Aim for this doctorate research is to explore the value of life story work (LSW) for people with Intellectual Disabilities aged 45 years and over, and the service providers who facilitate the LSW process.

Central questions are: What characterises the process and outcome in LSW? What value and effects has LSW had for older adults with ID and their interlocutors? What is the utility of LSW in person centred approach, and what is the value of including people with ID as advicers in the process of developing evaluation research?

Methods: to find characteristics, which can be used to measure the impact of LSW the research process starts with a phase of Delphi Techniques which contain interviews from 'experts' in LSW and participated research with use of an advisory group of people with ID. Results from phase one are used to develop phase two in this study. Self determination and accessible text for people with ID are salient in the research process.

Findings are supposed to give knowledge about the impact of LSW in services for people with ID 45 old and over. It will describe the connection between LSW and person centered approach and the value of including advisors withID in research process.

Topics for the interview

The interview I have asked you about will contain questions about your experiences, the approach and processes you observe in Life Story Work, influences, memories, challenges and purposes. You will also be asked to give some concrete examples from your practic.

Before the interview find place I will ask you to

1) confirm that you have received information about the study and your rights as an informant
2) give some personal detaljs about your background and
3) about your experiences in LSW.

1, 2 and 3 are filled in before the interview find place and given to the researcher.

Date, time and place for the interview we have agreed are:

Monday August 16th, 2010,

10.00 am - 11.30 pm (English time)

Consent statement for experienced life story worker

According to this project you match the criteria as an expert in life story work. Because you have confirmed the request to be interviewed, you are asked to give an informed consent before the interview find place. In the interview you will be asked about your expertise in Life Story Work. The data will be used to develop phase two in this study and it is a hope that knowledge from these interviews will increase the interest and professionalism in future Life Story Work in Health and Social Services.

Please give this consent form back to the researcher before the interview takes place. Your answers in the interview will be treated confidentially and securely stored. Please answer each statement concerning the collection and use of the research data.

I have read and understood the information sheet.	Yes ☐	No ☐
I have been given the opportunity to ask questions about the study.	Yes ☐	No ☐
I have had my questions answered satisfactorily.	Yes ☐	No ☐
I understand that I can withdraw from the study at any time without having to give an explanation.	Yes ☐	No ☐
I agree to the interview being tape-recorded and to its contents being used for research purposes.	Yes ☐	No ☐
I agree to being identified in this interview and in any subsequent publications or use.	Yes ☐	No ☐

Signature: _____

Place:_____Date:_____2009

Personal details

1.1 Your name:

1.2 Gender:

1.3 Email address:

1.4 Tel. numbers:

1.5 Profession:

Education

2.1 Current working place and country:

2.2 Number of years you have been working in services for people with intellectual disability:

Experience

3.1 How many **years** have you done life story work (LSW)?

3.2 Can you try to give me an estimated number of people you have done LSW together with?

3.3 Which **types of disability** have the storytellers you usually do LSW together with?

If the persons have intellectual disability, does they...(mark the right alternative)

3.3.1 Live in institution:

3.3.2 Live in own home or public accommodation where they receive public services?

3.3.3 Live home with family and receive daily services?

3.3.4 Live alone and have a personal budget?

3.4 What other persons with disability have you done LSW with than persons with intellectual disability?

3.5 What has the usual **age range** been of SRs you usually do LSW together with?

3.6 Is there any LSW **network** in your country?

3.6.1 If yes, who is running this ((internet) address, tel.num.)?

Heartfelt thanks for your information and please remember to send this papers before the interview.

All the best from Britt-Evy Westergård

Appendix 2: Consent statement for interlocutors in life story work

Title of study: Life story work - a new approach to the person centred supporting of older adults with an intellectual disability in Norway? - A qualitative evaluation of the impact from life story work on storytellers and their interlocutors

The researcher's name: Britt-Evy Westergård, a PhD student at the University of Edinburgh. E-mail: bew@aldringoghelse.no. Mobile +47 993 56 380

You are asked by the storyteller to be his/her interlocutor.
You have confirmed the request and are interested in participating.
You manager have approved your participation.

Data collected in the study will be treated with caution and stored in a secure manner.

I want to join as a participant in this study	yes ☐	no ☐
I understand the information I have received	yes ☐	no ☐
I have had the opportunity to ask and are satisfied with the answers	yes ☐	no ☐
I understand that I at any time can withdraw from the study and that I do not need to give a reason for this	yes ☐	no ☐
It is okay that I can be recognized while data is collected and analyzed	yes ☐	no ☐
I agree that the interviews with me can be tape recorded	yes ☐	no ☐

Signature: _____

Location: _____ ____ Date: __ \ ___2011

Appendix 3: Consent statement for the storyteller

Research project title: *Life story work - a new approach to the person centred supporting of older adults with an intellectual disability in Norway? - A qualitative evaluation of the impact from life story work on storytellers and their interlocutors*

Researcher Name: *Britt-Evy Westergård, PhD student at Department of Social Work, University of Edinburgh. Email: bew@aldringoghelse.no. Mobil 993 56 380*

Please take your time to make your decision.
Material gathered during this research
will be treated as confidential and securely stored.
It will be deleted 6 months after the study is finish.
Please answer each statement
concerning the collection and use of research data.
Give this consent form back to the researcher
before the first interview takes place or at the information meeting.

I want to take part in this study.	Yes	☐	No	☐
I understand the information that I have received in written and verbal form.	Yes	☐	No	☐
I have had the chance to ask questions and I'm satisfied with the answers.	Yes	☐	No	☐
I understand that I can at any time withdraw from the study. I do not need to give any reason for my decision.	Yes	☐	No	☐
I agree to being identified during the data gathering process.	Yes	☐	No	☐
I agree to the interview being tape-recorded and to its contents being used for research purposes.	Yes	☐	No	☐
I have spoken to someone I trust about this agreement.	Yes	☐	No	☐

My signature: _____

Signature of the person I have discussed my decision with:

_____

Place: _____ Date: ______2011

Appendix 4: Consent statement for recording films in life story work

Title of study: Life story work - a new approach to the person centred supporting of older adults with an intellectual disability in Norway? - A qualitative evaluation of the impact from life story work on storytellers and their interlocutors

The researcher's name: Britt-Evy Westergård, a PhD student at the University of Edinburgh. E-mail: bew@aldringoghelse.no. Mobile +47 993 56 380

Please take your time to make your decision.
The film clip you records from the meeting should be send every week in an mail to the researcher.
The film will be used to observe how you talk together in the meeting
The film will be deleted 6 months after the study is finish.
Please answer each statement
concerning the collection and use of research data.
Please give this consent form back to the researcher
before the first interview takes place or at the information meeting.

I agree to film three of our meetings	yes	☐	no	☐
I have understood the information I have received	yes	☐	no	☐
I have had the opportunity to ask and are satisfied with the answers	yes	☐	no	☐
I understand that I at any time can withdraw from the study and that I do not need to give a reason for this	yes	☐	no	☐
It is okay that I can be recognised while data is collected and analysed	yes	☐	no	☐

Signature: _____

Location: _____ ____ Date: __ \ ___2011

Appendix 5: Scale -faces

Appendix 6: Interview schedule for semi structured interviews with experienced service providers in life story work

Phase one

Ask if they have with them papers/questions sent in advance?

-approval, personal details and experiences

Start tape-recorder!

Record the name of the interviewee and interviewer, date, time and place for the interview.

1 Experiences

1.1 Why did you **start** to do LSW?

1.1 What is your **motivation** for continuing?

1.2 Could you tell me one story about LSW you remember as a **negative experience**?

1.3 Could you tell me one story about LSW you remember as a very **positive experience**?

I wish to explore some of the theoretical ideas you use in your approach of LSW - and I hope this is okay for you. If you do not have any clear theoretical frame for your work, that's okay - but then I will ask you to tell me about what you do and why you do it...is this okay for you? First in this part of the interview I will ask you about...

2 Description of the approach and the process in LSW

2.1. Could you very briefly **describe how you do** LSW?

2.2. Does this approach or method have a particularly **name**?

2.2.1. Why do you use this name?

2.3. Can you give me a brief overview of the **process** you go through with SR?

2.3.1. Is this process you have described a kind of a **fixed process** when you facilitate LSW - a kind of stepwise process?

2.4. Are there any well- known **theories** in psychology, sociology, pedagogic etc. you build your approach in LSW on

2.4.1. If yes, **which** are these theories? - If you don't remember the theories names, could you briefly tell me why you use the approach you do?

2.5. How do you **engage the SRs** to start and go through the process of LSW?

2.6. What style of **communication (techniques)** do you use to prompt the persons to tell their story?

2.7. In which way does the SR's ability to **communicate verbally** have an impact on the methods that are used?

2.8. How important do you think it is that **you trust** what SRs tells you in LSW - even if you are not sure about it?

2.8.1. What do you want to do if you positively know that parts of the story are wrong?

2.9. Do the SRs always make **products** like for example photo-album, tape or film recording in LSW?

2.9.1. If yes, which **products are usually made** and what is the main reason for 'this' to be made?

2.10. Is SR always **present** in LSW about them self?

2.10.1. If not, what are the main **reasons** for this?

2.11. What is the difference in LSW when SP does it for the person and when the person is helped with it?

2.12. Which **education** and role does facilitates in LSW usually have where you work?

2.12.1. Do they have some **formal training** in LSW?

2.13. What other **important persons** (e.g. family, former SP[1]s) do you usually ask to help SR to explore their stories?

2.14. Are there other **sources** (library, archives etc.) that are important when you do LSW?

2.15. How often are LSW **repeated** with a SR? (E.g. every second year, when the person is 40-50-60…, when SR ask for it, when SR move to a new place etc.)

2.15.1. Is there any **time** in SR lifespan you think **LSW it's more important** than other times, eventually why do you think this?

2.16. How many **hours** do you usually use from start to the end of LSW for one SR?

2.17. What do you think are especially good/**benefits with the methods** or approach you use?

2.18. Is it anything you want to **change** in your approach or methods? - Eventually why?

[1] Service Provider

3 Memories

3.1 Have you been surprised by some SRs **memories**?

3.1.1. If yes, how?

3.2 How **far back** does SRs usually remember?

3.3 Which **period** does SRs usually talk about in LSW *(specify)*:

3.3.1 Do they often-some time or never talk about their **past**?

3.3.2 Do they often-some time or never talk about the **present time?**

3.3.3 Do they often-some time or never talk about the **future?**

3.4 Have you observed any differences in memories for persons that have been raised in **institutions versus** those who have risen in a **family home** - eventually which?

3.5 Have you experienced any differences in the person's ability to do LSW depend on their **background** from an institutionalized life or not?

3.6 Have you observed any **changes** in SRs memories after LSW?

3.6.1 If yes, which changes, and have these changes **influenced** other things in the person's daily life?

Influences

4.1 How do you take care of **autonomy** in the sense of maintaining respect of the individual's ways of doing things in the LSW?

4.1.1 Could you give one **example** where you think this was difficult, but was managed in a good way?

4.2 Do you think SR's could do LSW **independent** your facilitation?

4.3 Have you come across people's stories about abuse, crime or other **sensitive information** the time you have facilitated LSW?

4.3.1 If yes, could you give me one **example** about this and what you did related to the information you was given?

4.4 Have you a strategy to **manage disclosures (avsløringer**) and what do you usually do in these situations?

4.5 In which way do you think the **environment** SR live in influence a) the way the stories are told to you? And b) the contents of the stories that are told?

4.6 **How important** is LSW in the service where you work? For example, is LSW basic for the service providing or is it a leisure activity the service does when they have time? Would it be any LSW in the service if you did not do it?

We are near the end of this interview now!

5 Purposes and impact of doing LSW

5.1 How important do you think LSW is for (*Answer categories are: very much, some, very little and none)*

5.1.1 - The person **identity development?**

5.1.2 - The persons **self-esteem?**

5.1.3 - Abilities to **self-determination**

5.1.4 - To express and be conciseness about own **life goals and whishes?**

5.1.5 - To feel **self-confident?**

5.1.6 **-**general **well-being and happiness**

5.2 Which **emotions** do you often observe in SR when you facilitate LSW?

5.3 What do you think is the most **valuable information SPs get** from LSW?

5.4 Who **decides** how the information from LSW can be used?

5.5 Is LSW to find as a **goal** in SRs **service or individual plan or care plan**?

5.6 Is information from LSW used in services given in **seriously sickness or in the process of life ending**?

5.6.1 If yes, can you give me one **example**?

5.7 Does LSW impact **SPs**, if yes, in which way?

5.7.1 -**attitudes**?

5.7.2 -**knowledge**?

5.7.3 -**practice**?

5.7.4 - **verbal or nonverbal communication** in interaction with SR?

5.7.5 - **concerns** for the SR's future?

5.7.6 -other **changes** you have seen?

5.8 How important do you think LSW is in **Health and Social service** in general? *(Answer categories are: very, some, very little and none)*

5.8.1 If yes, why do you think this?

5.9 Have you experienced that SRs documented stories have **impacted political decisions** in health and social services or other parts of the society?

5.9.1. If yes, in which way?

5.10 Have you observed **other impacts** of LSW in SPs or SRs?

And here comes the last three questions!

6 Challenges

6.1 What are the **biggest challenges for SR** when he/she do LSW?

6.2 What are the **biggest challenges for SP** to facilitate a good LSW process?

6.3 **Other challenges** in LSW?

End

Thank you very much for helping me and giving me your time. Can I finally ask you if there is any aspect of your experience about LSW that has not been covered in this interview?

It is 67 main questions and 76 questions in all, if they answer yes on 9 questions.

Appendix 7: Information and questions – for the interlocutors

In these sheets you will find:

- ✓ INFORMATION ABOUT THE STUDY
- ✓ CONTENTS OF THE INTERVIEW
- ✓ QUESTIONS ABOUT YOURSELF
- ✓ QUESTIONS ABOUT YOUR EXPERIENCES

The name of the study
Life story work - a new approach to the person centred supporting of older adults with an intellectual disability in Norway? - A qualitative evaluation of the impact from life story work on storytellers and their interlocutors

The researcher
Britt-Evy Westergård,
a PhD student at the University of Edinburgh,
employed at the Norwegian National Advisory Unit on Ageing and Health

Those who pay for the study are
Norwegian National Advisory Unit on Ageing and Health
and the Research Council in South East Health.

Supervisors at the University of Edinburgh are
Heather Wilkinson and Susan Hunter.

Project coordinator is
Øyvind Kirkevold
from the National Centre for Ageing and Health

Contents of the interviews:

It is one interview before you start
and one after you have done the lifestory work.
Britt-Evy is interviewing you
and record what you say on a tape.

In the interviews you will be asked about
the need for knowledge, attitudes
and procedures in your practice,
your knowledge of the person
you are interlocutor for
and the importance of identity strength
and personal development
related to this person.

When you have done the lifestory work,
you will be interviewed again.
Then there will be some new questions
about how you think it was
and the importance of lifestory work.

All the answers you give in the interviews
and the questions you answer in advance,
Britt-Evy will write into a PC.
This will be to a report which is called a Thesis.

The thesis is written in English
and delivered to the University of Edinburgh.
There will also be published something in Norwegian
that you and your staff can read.

Name and addresses
Your first name is ……

Are you male ……. or female……

The service that the lifestory work is done
……..

Email link to the location is ……

The phone number for the place is ……..

The name of the leader is ……

Education and employment:
What education do you have for working with people with disabilities?

What type of position you are today and how much power per cent?

How many years have you been working with the person you now are going to be a c-friend for?

Experience of lifestory work:
Have you previously made lfa itself or in conjunction with a user?

Do you have good computer skills?

Please live answers to Britt-Evy as soon as possible.

Thank you for your help.
Kind regards Britt-Evy Westergård

Appendix 8: PRE- and POST semi-structured interview-guide for interlocutors in life story work

Phase 2

Before the pre-interview starts:

Check if they have delivered or bring with them the **form of consent** and **sheets of questions** I asked them to fill out in advance.

Questions before the interview:

- Are there any special conditions you want me to pay attention to during the interview? For example, that you have a hardness of hearing; find it difficult to understand my accent or something like that.
- It would be nice if you could tell me when you do not understand the question.
- This interview is not to test your knowledge; the important thing is to acquire knowledge about your experience in connection with LSW process.
- The interview takes about 45 minutes.

Start the recorder

*Record: the **first name, date and place** of the interview.*

What is the first name of the person (X) you is an interlocutor for?

Service Provider relationship to the person who will do LSW

1/1b[2]. How well do you **know** X?

2/2b. How **equal** do you consider you and X are?

3/3b. How **exciting** do you think X is as a person?

4/4b. How much **respect** do you have for X?

5/5b. How well do you know X's **tolerance limits**?

6/6b. How well do you know X's **interests**?

7/7b. How well do you know the values **of X**?

8/8b. How much do you know about the **life cycle of X**?
9/9b. How **safe** do you feel together with X?
10/10b. How well do you **communicate** with X?

11. How much are you looking forward to being an interlocutor?

Perceptions of knowledge, attitudes and practices related to X

12. What is the most important **knowledge** you have about X?
12b. Have your role as an interlocutor impacted your knowledge about X in some degree?

13. Describe **attitudes** among the staff you think are important in their cooperation with X, and other people in the same situation.

13b. Have the knowledge you get through LSW in some degree impact your attitudes?

59b. Have the knowledge you get through LSW in some degree impact your **practical approach?**

Describe one thing you will emphasize in your collaboration with X in the following **situations**:

14. When an **individual plan** is created

15. When X is **angry** and frustrated

[2] The 'b.'after the number means that the questions are used in the post-interview. Numbers without b) are used in the pre-interview.

16. When X wants to have **fun**
17. When you are an interlocutor for X in the lifestory work
18. Are there any **situations you think can be difficult** for X during LSW?

18b. Have you experienced any difficult situations for X during LSW?

19. Are there any situations you think will be difficult for you during LSW?

19b.Have you experienced any difficult situations and dilemmas during LSW. If yes, what was it and how was it resolved?

I will make some **statements** that I ask you to answer:
20. It is enough that you know the service recipient's name, age and diagnoses to provide good support

21. One does not need education to be a good provider.

22. Users should decide who they should get help from.

23. You would fight for a user's right in a conflict between your employer and a user, even though this could mean that you were miss-liked by your manager.

Perceptions about the identity strength and personal development of X

24. How would you describe a person with a strong and positive identity?

25. Are these typical traits with X?

26. How different or similar is X's strength of identity compared to other people at the same age and with an intellectual disability?

26b. In the first interview I asked you to describe a person with a strong and a positive identity, which you compared to X. Have something happened with the identity of X in connection to LSW?

27. What do you understand with personal development?

28. Does this apply to X in some degree?

29. How different or similar is X from other people of the same age and with the same disability when it comes to personal development?

In what way is X similar or different?

29b. Earlier I asked you to describe what you understood by personal development related to X. Have something happened to X's personal development in connection with LSW?

Scale prompts: tap one of five faces that you see on the sheet. Number one is the angry one that is very unsecure or very bad, while number five is very secure or super good; the others are something in between number one and five.

30/30b. How much **sense of identity** do you think X has?

(Knowledge about him/herself: own personality, life goals, background, constraints and opportunities of the disability – has a personal 'style' in clothes, interests, perceptions, etc.)

31/31b. How **satisfied with life** do you think X is?
(Says that he/she is having a good life, talking about good experiences, expressing joy)
32/32b. How **self-confident** do you think X is?
(Self-secure, expressing a confidence in relation to his/her surroundings)
33/33b. How much **self-respect** do you think X has?
(Respect for her/himself, puts up boundaries from other peoples influences and doing good things for her/himself)

34/34. How great opportunities for self-**determination** does you think X has? *(Have clear opinions about what he/she wants in various contexts and is responsible for his/her decision despite opposition)*

35/35b. How distinct **desires and goals** for the future does X have? *(finish with the scale)*

36. How would you describe a **positive development** of older people with an intellectual disability?

36b. In the last interview I asked you to describe positive development of older people with intellectual disabilities, do you have more or different/other thoughts about this now?

37. How would you describe **negative development** of older people with an intellectual disability?

37b. In the last interview I asked you to describe negative development of older people with intellectual disabilities, do you have more or different/other thoughts about this now?

38. What can you do to encourage people you provide services for to get a **positive personal development?**

38b. In the last interview I asked you to describe positive personal development of older people with intellectual disabilities, do you have more or different/other thoughts about this now?

39. What can you do to encourage people you provide services for to get a **positive identity development**?

39b. In the last interview I asked you to describe positive identity development of older people with intellectual disabilities, do you have more or different/other thoughts about this now?

The value of LSW

40. How **important** do you think LSW is for adults and seniors with an intellectual disability?

40b. On a scale of 1-10, how important do you think LSW is in services for older people with intellectual disabilities?

41. How important is LSW **compared to individual planning (IP)** and the follow-up of IP?

43. Why do you think so **few services in Norway are using LSW?**

Observed changes during and after LSW

44b. Have you observed any **changes** in what X **talks about** now compared to before LSW?

If yes: what changes have you observed?

45b. Has LSW in any way influenced X's **nonverbal and verbal communication**?

If yes: In what way?

46b. **Empowerment** means that other people look at the person as qualified to talk for him/herself and to have meanings about other things or other people, have you observed any changes in the person`s **empowerment** in connection with LSW?

Experiences with LSW

(Question 18b and 19b)

47b. How did you **experience to do LSW** as it was taught in this project?

48b. Were you well enough **prepared for the task** as an interlocutor?

49b. What are the most **important experiences** you have from the processes in LSW?

50b. What **surprised you** most about the person you were an interlocutor for?

51b. How did the **book** about LSW work for you?

52b. If you think from a scale of 0-10, with 0 being very hard and 10 very hard; How **emotionally easy or hard** was it for you to be a interlocutor?

53b. On a scale of 0-10, how **fun** did you think it was to facilitate the life-story work? (with 0 being not fun at all and 10 very fun),

54b. To what degree do you think LSW may prevent psychic difficulties?

55b. Will you **continue** to do LSW in the service where you work?

56b. What are the most important **motivating factors** for establishing LSW in your service?

57b. In what other settings than those we have been talking about in this interview do you think LSW may be a positive contribution?

43/43b. Do you have any other comments in connection with this interview?

Appendix 9: Information and questions – for the storytellers

In these sheets you will find:

- ✓ INFORMATION ABOUT THE STUDY
- ✓ CONTENTS OF THE INTERVIEW
- ✓ QUESTIONS ABOUT YOURSELF
- ✓ QUESTIONS ABOUT WHAT YOU HAVE DONE BEFORE

The name of the study
Life story work - a new approach to the person centred supporting of older adults with an intellectual disability in Norway? - A qualitative evaluation of the impact from life story work on storytellers and their interlocutors.

The researcher
Britt-Evy Westergård,
a PhD student at the University of Edinburgh,
employed at the Norwegian National Advisory Unit on Ageing and Health

Those who pay for the study is
the Norwegian National Advisory Unit on Ageing and Health
and the Research Council in South East Health.

Supervisors at the University of Edinburgh are
Heather Wilkinson and Susan Hunter.
Project coordinator is
Øyvind Kirkevold
from the Norwegian National Advisory Unit on Ageing and Health

You deliver the sheets with your answers to Britt-Evy.

Contents of the interviews:

It is one interview before you start
and one after you have done the lifestory work.
Britt-Evy is interviewing you
and record what you say on a tape.
You can take a staff with you
if you feel unsafe.

In the interviews you will be asked
about family and friends,
about your interests,
if you have collected lifestories previously
and how you experience yourself.

You will be asked about self-determination
how you feel that your life is,
about your feelings
and if you like to tell stories.

When you have done the lifestory work,
you will be interviewed again.
Then there will be some new questions
about how you think it was.

All the answers you give in the interviews
and the questions you answer in advance,
Britt-Evy will write into a PC.
This will be to a report which is called a Thesis.

The thesis is written in English
and delivered to the University of Edinburgh.
There will also be published something in Norwegian
that you and your staff can read.

Questions

Have you signed and delivered
the paper with the consent: YES ... NO ...

Who helps you answer the questions below?

……
The name of the person helping you.
Do not respond to this and the next question if you do it alone.

Whoever helps you are:
Please mark the correct answer:

- one from staff
- my proxy
- one of my parents
- Britt-Evy
- other

Name and addresses

Your first name is …….

Are you male ……. or female.……

Your age is: ……..

The service that helps you to do lifestory work is

……..

Email link to the location is ……

The phone number for the place is ……..

The name of the leader is …….

Your home

If no one match,
write your answer after "others"

Do you live in a group home	yes	no
Do you live in an apartment that you rent	yes	no
Do you own your property	yes	no
Do you live in the nursing	yes	no
Do you live in a sheltered place	yes	no
Do you live at home with mom and dad	yes	no

Other:

Which schools have you completed?

Primary: yes no

Secondary: yes no

High school: yes no

Vocational training: yes no

”Folk college”: yes no

Other:

Have you attended special schools all the time: yes no

Have you attended both special and normal schools: yes no

Where was it best for you – at a special school or at a normal school?

Do you read? yes no

Do you like

- to read newspapers yes no
- to read books with text yes no
- to read books with only picture yes no
- to read about politics or sports yes no
- that someone reads to you yes no
- to watch movies yes no

Have you ever lived in one or more institutions?
How many institutions have you lived in?

How old were you when you moved into an institution for the first time?

How old were you when you moved out of the institution?

What was the worst of living in an institution?

What was the best thing about living in an institution?

Experience
What have you worked with before?

How old were you when you started working?

How old were you when you stopped working?
(Not answer to this if you are still working)

Are you at a day center for seniors? yes no

Please live answers to Britt-Evy
as soon as possible.
Thank you for your help.

Greeting Britt-Evy Westergård

Appendix 10: PRE and POST semi-structured interview-guide for storytellers in life story work

Phase 2

Before the pre-interview starts:
Check if they have delivered or bring with them the **form of consent** and **sheets of questions** I asked them to fill out in advance.

Before the interview:
- Are there any **special conditions** you want me to pay attention to during the interview? - For example, that you have hearing difficulties; find it difficult to understand my accent or something like that?
- The questions I am going to ask you, **is not a test**, I'm just interested to know what you think about various things and to tell me about yourself.
- If there are questions you do **not know how to answer**, or do **not want to answer**, it's okay to say that. You do not need to give me an answer to on every question I ask, but I hope you will answer as much as you can.
- If I ask you something you do **not understand,** then it is me who have not made good enough questions.
- If you get tired, we may take a break.
- The interview takes about 30 minutes.
- Do you have any **questions before we start**?

Start the recorder
*First record: the **first name, date and place** of the interview.*

Collected memory and communication of life stories

1. Do you have pictures in your own home from **when you were a child**?

If you do not have any pictures from your childhood, do you think somebody in your family have pictures of you?

2. Do you have **pictures** of **your biological family** in your own home?

3. Do you have **photo albums at home**?

Have you shown these to staff and other people?

4. Have you **told** any of the staff about your life, things that have happened in your life and things you did before?
4b[3].Have you **shown the things you have made** in the LSW to somebody?
If yes, how did you like to do that?

50b. Did you meet someone from your family in connection with the LSW?

Social interests and networks

5/5b. What do you **like to do** after your work/day center these days?

6. Do you have support during your **leisure time**?
7. Do you have one or several very **good friends**?

If yes:
- How often do you meet?
- Where do you meet?
- Do they often visit you in your home?

What do you use to do when you are together?

8. Do you have a **boy/girlfriend**?

9. Do your parents **still live**?

If yes:
- How often do you meet them?
- Where do you meet?
- Do they often visit you in your home?
- What do you use to do when you are together?

10. Do you have **siblings**?

If yes:
- How many?
- Are they older or younger than you?
- How often do you meet them?
- Where do you meet?
- Do they often visit you in your home?
- What do you use to do when you are together?

[3] The 'b.' after the number means that the questions are used in the post-interview. Numbers without b) are used in the pre-interview.

Identity and self-understanding

11/11b. I am wondering if you can tell me **about yourself**. You may tell me exactly what you want, when I ask you "Who are you?"

51b. Who in the staff group, your family or friends know you best?

12. There are different reasons for why we have become the persons we are today. That is how it is for everybody. I am now going to ask you some questions about this. You may answer yes, no or pass, if there are questions you do not know how to answer. In addition to the usual questions, I have some silly questions I ask in between the real one- is this OK for you?

What do you think is part of the reason why you have **become the person you are**, is it because of...

a) your family?
b) things you have learned?
c) Donald Duck?
d) things you have experienced?
e) staff you know now or have known before?
f) the King?
g) your disability?
h) music you like?
i) people that loves you?
j) the sun and the moon?
k) your job?
l) schools you have attended?
m) places you have lived? (Buss 2001:.97)

12b. what do you think is the basis for the person you are today?
e.g is it your family , things you have learned, experiences you have had, people you have met and like. Is it because of your disability, or have you become the person you are because of your work and your friends?

13/13b. Do you know someone that is very **similar to you?**
If yes:
What are the similarities between you?

14/8. Have you ever **wished you were someone else**?
If yes:
Who should that have been?
Why do desire to be this other person?

15. Do you have any **clothes** you like to wear?

16. Do you feel **different or similar to** everyone else? (Ask more about the answer/discuss the answer?)

17. I'm going to say two words and I want you to say the word that describes you best

Are you
- young or old
- foreigner or Norwegian
- healthy or ill
- big or small
- male or female
- normal or abnormal
- happy or sad

17/17b

Do you like
- surprises or do you like it best when you know what will happen?
- to be at home most of the time, or to travel?
- best to be alone or to be with others?
- to do many things every day or would you rather sit quietly and relaxed?

Quality of life

18/18b. How **satisfied** are you with:

Prompts: tap one of five faces that you see on the sheet. The angry one is very bad and the very smiley one is very good, the others are something in between.

a) Your life as it has been? /18b: when you think about what you have told in the LSW?
b) Your life as it is now?
c) The place you live?
d) Opportunities to do things alone? (not 18b)
e) Opportunities to do things in your spare time? (not 18b)
f) Staff who helps you at home?/18b: the help you get from the staff?
g) Staff at the day centre / job? (not 18b)
h) Your health?

19/19b. How **satisfied** are you with yourself these days?

Finish with the sheet

20/20b. Do you have **nice people around you**?

21. Do you feel free to **do exactly what you like to do**?
If not:
Why not?

22. Do you feel free to **buy what you want**, or do you get a fixed amount of money you may use every week?
How satisfied are you with this?

52b. Which people do you really **like to be together with**?

53b. What do you most of all **like to do**?

Safety and (self-) respect
Prompts: tap one of five faces that you see on the sheet. The angry one is very insecure and the very smiley one is the safe and secure one, the others are something in between.

23. In general **how safe do you feel?**

Finish with the sheet

24. When, or in which situation do you **feel most safe**?
May you say something more about that?

25. When, or in what situation **do you feel less safe**?
(or: what situations are your most afraid of)
May you say something more about that?

26. Are there any things you do not dare to do because you feel afraid?
(Examples)
What does it take to make you feel safe in these situations?

27. Do you dare to speak up when you do not **agree with the staff**?
Is this **easy or difficult** for you?

28/28b. What can you do to be **extra good and kind to yourself?**

29/29b. Do you feel that you **love/like yourself**?
If not: why?

30/30b. Do you feel like an **important person**?
(McA's theory)

31. Can you try to tell me who you believe really **loves you**? (McAdams's theory)
Have you thought about **why** they love you?

32. Who are you **most fond of**? (Who is that person)

33. Do you often find that other people **ask you for help**? (McAdams's theory)

34. What is the **best about you** (their name)?

54. Have you got more knowledge about yourself after the LSW?
If yes:
May you tell me more about this?

Self-determination and person centered care
35/35b. Who do you feel **decide things in your life**?

36/36b. **Who decides** what you are going to do
a) at the day center / job?
b) in your home?

37. Can **you decide** who among the staff that provides to you the help you need?
If not:
Do you wish that you could decide this?
Or is it okay as it is today?

38. Do you know what an **individual plan** is? It is also called IP, or Service Plan.
Explain: An individual plan will help you to find out what help the municipality will provide for you to manage your daily life, have a good health and to do things you like. Everyone that helps you, should know about this plan, and all of them should work together to give you the help that is written in the plan.

39. * Do you **have an individual plan**?
a) Did you work with the plan together with some of the staff?
b) Do you remember what the IP contains?
c) Do you get the help the plan describes? If not, why do you think it is like that?
d) Can you change the plan if you want it?
e) Are you satisfied with the plan you have today?

40. Do you know what **human rights** are?
Explain: It is the right you have to make decisions in own life, get the help you need and be treated well by others. Everyone has rights. We also have obligations related to our rights, but we will not talk about this here.

41. Has anyone told you about the **rights you have as a service user** in a municipality?

42. Have you been **told** about?
- Your right to get help?

- Your right to decide for yourself?
- That you can pay half price on the bus when you are retired
- That staff that are supporting you may get a free ticket at the cinema?

43/43b. Do you experience/feel that the **staff listens** when you have something important to say?

55b. Are there things you desire to make decisions about yourself, that someone/staff is preventing you from deciding /**stopping you to decide**?

Telling (Same questions as Phase 1)

44/44b. Do you like to **talk about your past** (the old days, when you were a child or a youngster)

45/45b. Do you like to talk about the present **time** (things nowadays or things that have happened this week?)

46/46b. Do you like to talk about the **future**? (What your wishes are for the future)

47/47b. Do you like to **tell about yourself**?

48. Have you ever been interviewed before?

Additional questions for interview AFTER the lifestory work

Experience of life story work in this project (research question 1)

56b. Has the LSW **changed anything** in your life?
If yes: what?
Prompt: do people speak to you in a different way? Are the staff different? Are other people different?

57b. Have you experienced any **changes in yourself** (after you started the LSW)
If yes: in what way?
Prompt: Things you are thinking more about now? Things you do now that you not did do before the LSW? Have you learned something new?)

58b. Have you experienced any **changes in your interlocutor** after you started with life story work?
If yes: what kind of changes?

59b. Have you experienced any **changes in your staff** that you meet every day?

Evaluation of the process

60b. **How was it** to do life story work?
Prompt: did you like the way you and your interlocutor worked together? Did you have a good time when you were together? Did you learn something new - what?

61b. What was **most fun** with the LSW?

62b. Did you experience anything you think was **difficult in the** LSW?
If yes:
- Can you tell me what that was?
- How did you solve it?

63b. What do you think about the **book you used**?

64b. What do you think about the album (or what) **you made in the LSW**?
Do you think you will use it?
Are you proud of your work?

65b. Will you **continue** to do LSW?
Why?

66b. Can you do LSW **alone** or do you think you need an interlocutor as you have had this time?

67b. What was the **best about having an interlocutor**?

49/49b. Is there anything else you want to say in this interview?

Appendix 11: Experiences of life story work in adult/elderly people with intellectual disabilities and interlocutors' from staff

You are invited to take part in a study about life story work
and to tell Britt-Evy your experiences about this.

Life story work is to write, speak, record movies or collect pictures of personal narratives
you have about past, present or future.

You will get help from an interlocutor
which you choose from the staff.
The manager of the service must approve
the one you choose.

You and your interlocutor are interviewed
before and after your life story work.
You will meet about 2 hours a week
for roughly 8 weeks.
You decide where you meet
and how long your meeting shall last.

You decide how you want to work with your life stories;
if you just want to talk and use a tape-recorder,
to make an album, film or
to use a computer.

You talk with your interlocutor
how you will do your life story work
so you get the help you want.
You decide what you want to tell the interlocutor
and other people about your life.

You and your interlocutor will have to send
an e-mail to Britt-Evy every week.
In that e-mail you write an answer to the questions
on the sheet Britt-Evy has given you.

Some of you will be asked to record a film
from your meetings.
Tell me if you want to do that.

Before you start, you will get a booklet
telling you how to work with your life stories.
You keep the book
and the material you have made
from the life story work.

Your participation
will be a help to others.
The results from the study
will be written in English and Norwegian.
It will be told about the study
at conferences in Norway and abroad.

I look forward to working with you.

Kind Regard
Britt-Evy